Reasons and Avoidability of Hospitalisations at the End of Life

Perspectives of GPs, Nurses and Family Carers

Ria de Korte-Verhoef

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Chapter 1

General introduction

Introduction

Hospitalisation at the end of life

Around half of patients are transferred from home to hospital in the last three months of life in the Netherlands and in Belgium, and most of these hospitalised patients also die in hospital.[1;2] The proportion of 33% of deaths taking place in hospital in the Netherlands is relatively low in comparison with other countries, such as Belgium (52%), Sweden (63%) and the UK (58% in England and 63% in Wales).[3] In interpreting this, it should be taken into account that in the Netherlands 34% of deaths take place in homes for the elderly and nursing homes, which is a high proportion in comparison with other countries.[3] The proportion of patients who died at home was 28% in the Netherlands in 2003, 34% in Italy in 2002, 33% in Portugal in 2005, 30% in Canada in 2004, 23% in Belgium in 2007, 21% in England in 2010 and 17% in Norway in 2008.[3-6]

Factors associated with a greater likelihood of hospitalisation at the end of life include being male, multiple morbidity, infections and an absence of a palliative-centred treatment goal or having a general practitioner (GP) who was not aware of the patients' wishes concerning the place of death.[1;2] However, these earlier studies did not show what the most important reasons were for hospitalisation. Until 2010, the only available data about the reasons for hospitalisation were from lung cancer patients and nursing-home patients. For lung cancer patients, the most important reasons for hospitalisation were dyspnoea, pain, an inability to cope at home and an altered level of consciousness.[7] For nursing-home patients, the most common reasons for potentially avoidable hospitalisations were cardiovascular and respiratory reasons.[8]

Hospitalisation at the end of life is of concern to society, and affects healthcare quality and costs. From the perspective of society, it is well known that most people want to be cared for and die at home. In the Netherlands, home is the preferred place of death for 83% of people, the highest proportion in a comparison with other European countries, which gives figures ranging from 51% to 76% [9] Hospitalisation is also of concern from the perspective of the quality of care at the end of life because a high number of hospital days at the end of life and hospital deaths are considered to be an indicator of poor quality of care.[10] In addition to this, a substantial proportion of healthcare costs are incurred in the last year of life and in hospital. In the Netherlands, the costs in the last year of life are 13.5 times higher than in the previous years of life, and half of these costs are related to hospital care.[11] In the United States, a proportion of 30% of all Medicare expenditure (Medicare is the health insurance for people over 65) on insured people was attributed to the last year of life, with one third of that expenditure occurring in the last month of life.[12]

Because of the high number of hospitalisations at the end of life and the high proportion of Dutch people who prefer to stay at home and to die at home, it is important to know more about the avoidability of hospitalisations. A British study based on hospital chart analyses suggested that 33% of hospitalised patients who were identified as being in the last year of their life could have been treated at home.[13] Other studies report on hospitalisations of nursing-home residents. In one study, a proportion of 40% of hospitalisations of nursing home residents were estimated as potentially avoidable[14] and in another study 67% of hospitalisations were estimated as potentially avoidable.[8] It was suggested that many of the acute problems could be treated in the nursing homes and that this would result in lower costs for the health insurance.[8] These previous studies provide insight about the avoidability of hospitalisations of nursing-home residents and the avoidability of patients being admitted to hospital as assessed from the clinicians' perspective. However, empirical data about whether and how hospitalisations at the end of life can be avoided from the perspective of GPs, nurses and family carers are lacking.

Palliative care in the Netherlands

When considering the avoidability of hospitalisations at the end of life, it is necessary to view this in the light of the approach to palliative care. The estimated proportion of people who are in need of palliative care varies from 57%[15] to 70%[16] of all deaths in the Netherlands. The proportion of 57% is based on all people who died of chronic diseases, including cancer.[15] The proportion of 70% is based on a study in which physicians assessed whether the patient had died non-suddenly. Taking these proportions into account, it can be estimated that of the 140,813 people who died in the Netherlands in 2012, around 80,000 to 100,000 people might have had a need for palliative care.

Palliative care is defined as[17] an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;

- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Although caring for the dying always was a part of standard health care, this care attracted special attention in around 1990. It was then that the first inpatient hospices started providing specialised palliative care in the Netherlands. Since 1996, the Dutch Ministry of Health, Welfare and Sports has paid a great deal of attention to palliative care. From this starting point, there has been a strong emphasis on the integration of palliative care in the general healthcare system. This is confirmed in the latest letter of the Dutch Ministry of Health on 11 December 2013, in which it is stated that "palliative care is part of the standard care. The character of palliative care is generalistic: care providers such as GPs and nurses, and institutions such as nursing homes and homes for the elderly and also hospitals need to have the knowledge to provide good palliative care and fast access to specialist palliative care if needed".[18] This means that GPs in the Netherlands have a high degree of personal responsibility for palliative care. Most other European countries tend to a more specialist view of palliative care. This is the case in Belgium, Spain and the UK, where palliative care provision is often shared with palliative care home teams.[19;20] In addition, GPs in the Netherlands can acquire additional certification for palliative care (*kaderarts*), while palliative medicine is a separate specialty for physicians in the UK, Ireland, Poland, Latvia and Norway.[21]

In the latest Ministerial letter, it is also mentioned that it is important for palliative care to be provided close to the place where the patient lives, which is mostly at home, and GPs and (community) nurses have a pivot role in the home.[18] GPs have mostly known their patients for a long time[22] and nearly all GPs visits their patients more than once in the last three months of life.[23] In the out-of-hours service, GPs work in shifts as locums in regional GP cooperatives.[24] Nursing care can be provided by community nurses or certified nurse assistants. Early in the disease process, nurses can provide advice, education and information to the patient and their family; this is often limited to, on average, five hours in the total illness process.[25] In addition to this, in some regions case managers for palliative care are available for whom there are no limitations on the amount of patient support.[26] In the Netherlands, all patients have compulsory health insurance, which provides unlimited access to the GP. For specialist care, such as hospital care, the GP has the function of gatekeeper, which means that in non-acute situations GP referral is needed for hospital care.

Objectives and research questions

This thesis consists of two parts:
1. Reasons for hospitalisations;
2. Avoidability of hospitalisations at the end of life.

The general objective of the first part is to provide insight into the reasons for hospitalisations at the end of life. Up to 2010, the only available studies about the reasons for hospitalisation covered lung cancer patients or patients who resided in nursing homes, so more information was needed on the general group of patients who died non-suddenly and resided at home. In addition to this, because there has been a shift from the 24-hour availability of GPs to GP care in office hours plus the out-of-hours regional GP cooperatives, there is a need to know what the reasons were for the referral of palliative care patients from the out of-hours GP cooperatives. Since most patients prefer to be cared for and stay at home up to the end of life, this may lead to a burden on family carers. Consequently, the burden of family carers can also be a reason for hospitalisations at the end of life. Therefore, Part I focuses on the reasons for hospitalisation from the perspectives of GPs, GPs working in the GP cooperatives, and the family carers. Accordingly, the research questions addressed in Part I are as follows:
1. What are the reasons and characteristics for hospitalisations at the end of life?
2. What are the reasons for hospital referrals of patients in need of palliative care for whom an out-of-hours general practitioner was called?
3. Is the degree of burden for family carers associated with hospitalisation in the final week of a patient’s life?

The general objective of the second part is to provide insight into the avoidability of hospitalisations at the end of life. One study of avoidable hospitalisations was based on chart reviews of patients who resided in the hospital while other studies were about nursing home patients. To unravel the avoidability of hospitalisations of patients who reside at home, it is also important to know the opinion of GPs, nurses and family carers as to whether and how hospitalisations of patients at the end of life can be avoided. Therefore, Part II of this thesis focuses on the avoidability of hospitalisations at the end of life:

4. Whether and how hospitalisations at the end of life can be avoided in the last three months of life, according to general practitioners?
5. How can hospitalisation at the end of life be avoided, from the perspective of the GPs, community nurses and family carers?
6. Palliative home care provided in a generalist palliative care model is associated with no hospitalisation in the last month of life

Methods

To explore the reasons and avoidability of hospitalisations of patients residing at home, we conducted research of the perspectives of GPs, community nurses and family carers. Two studies were performed for this thesis.

1. We started with a retrospective descriptive chart study covering a one-year period (1 November 2005 to 1 November 2006) in out-of-hours GP cooperatives in the Amsterdam region (Netherlands). The total number of patient calls to the out-of-hours GP cooperatives during the one-year study period was 137,828. The records of all phone calls were screened electronically. The content of the 2304 records identified as calls for patients in need for palliative care was subsequently examined by a GP with extensive experience in palliative care. We included all contacts in which any mention was made of palliative care needs, palliative medication, remarks about terminal illness etc. This resulted in a list of calls for 553 different patients in need for palliative care, 13% of who were referred to a hospital. These data were used to answer research question two.
2. A mixed-methods study was conducted using a sequential strategy.[27;28] The sequential strategy consisted firstly of a quantitative design using a nationwide retrospective cross-sectional questionnaire study among GPs. Of all 8896 registered GPs in the Netherlands, a sample of 2000 were asked about their last deceased patient who died non-suddenly. Of these 2000 GPs, 1200 were asked about their last deceased patient who was hospitalised, for at least one night, in the last three months of life. If the patient underwent multiple hospitalisations,

the GP was asked for the last hospitalisation before death. In addition to this, the remaining 800 of the 2000 GPs were asked about the last deceased patient who was not hospitalised in the last three months of life. The main family carers and the nurse, if involved, were also asked to fill in a questionnaire. Secondly, a qualitative study was conducted, with in-depth interviews with GPs, nurses and family carers. Based on the patients' characteristics, as noted in the quantitative questionnaire study, 20 hospitalised patients and 10 non-hospitalised patients were purposively selected. This resulted in 59 in-depth interviews with 26 GPs, 15 nurses and 18 family carers. The quantitative part of this mixed-methods study with the GP questionnaires provided answers for research questions one and six. The mixed-methods study with the questionnaires and in-depth interviews among GPs and family carers were used to answer research question three. The mixed-methods study with questionnaires and in-depth interviews among GPs provided answers to research question four. Finally, the qualitative part of the mixed-methods study with interviews among GPs, nurses and family carers was used to answer research question five.

Outline of this thesis

The chapters of this thesis are based on published or submitted articles in peer-reviewed scientific journals.

Part 1 Reasons for hospitalisations at the end of life
Chapter 2 presents the reasons and characteristics of hospitalised cancer patients in comparison with hospitalised non-cancer patients.
Chapter 3 describes the reasons and characteristics of hospital referrals of palliative care patients for whom an out-of-hours general practitioner was called.
Chapter 4 explores the degree and types of burden of family carers in the final three months of a patient's life. In addition to this, it explores whether the degree of family carers' burden was associated with hospitalisation in the final week of a patient's life.

Part 2 Avoidability of hospitalisations at the end of life
Chapter 5 describes whether and how hospitalisations can be avoided in the last three months of life, according to general practitioners.
Chapter 6 investigates how hospitalisation at the end of life can be avoided, from the perspective of the GPs, community nurses and family carers.

Chapter 7 explores the differences in palliative care delivery between patients who were hospitalised and those who were not hospitalised in the last three months of life.

Chapter 8 is the final chapter in which the major findings are discussed. In addition to this, recommendations for practice, education, policy and research are provided.

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Part 1

Reasons for hospitalisations at the end of life

Chapter 2

Reasons for hospitalisation at the end of life: differences between cancer and non-cancer patients

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Abstract

Backgroud

Many patients are hospitalised during the final phase of life, even though most prefer to receive care at home until the end.

Aim

This study aimed to explore the reasons and characteristics of hospitalisation in the final three months of life for patients who died non-suddenly, with a comparison between cancer patients and non-cancer patients.

Methods

A nationwide retrospective cross-sectional survey among Dutch general practitioners.

Results

Of the 317 hospitalised patients, 65% had cancer. Most common reasons for hospitalisation in the final three months of life were respiratory symptoms (31%), digestive symptoms (17%) and cardiovascular symptoms (17%). Seventy-three percent of patients experienced an acute episode before hospitalisation and for 46% of patients their own GP initiated the hospitalisation. Compared to non-cancer patients, cancer patients were significantly more likely to be aged less than 80 (81% versus 46%), were more likely to be hospitalised because of digestive symptoms (22% versus 7%), were less likely to have a curative treatment goal before the last hospitalisation (6% versus 22%) and were less likely to die in hospital (22% versus 49%).

Conclusion

Respiratory problems were the most common reasons for hospitalisation in the group of patients as a whole. Digestive problems were a frequent reason for hospitalisation in cancer patients, and cardiovascular symptoms in non-cancer patients. Hospitalisation can therefore be anticipated by monitoring these relatively common symptoms. Also, timely communication with the patient is recommended about their preferences for hospital or home treatment in the case of an acute episode.

Introduction

Many patients are hospitalised during the final phase of life,[1,2] even though most prefer to receive care at home.[3-5] The proportion of patients who are transferred from home to hospital in the last three months of life is 55% in the Netherlands[1] and 60% in Belgium[2]. In Canada, 68% are transferred to hospital in the last six months of life.[6]

Factors associated with a greater likelihood of hospitalisation at the end of life include being male, multiple morbidity, infections and patients for whom there was no palliative-centred treatment goal or where the general practitioner (GP) was not aware of the patients' wishes concerning the place of death.[1,2] The reasons most commonly given for the hospital referral of palliative care patients for whom an out-of-hours GP cooperative was called were digestive problems, endocrine/metabolic/nutritional problems and respiratory problems.[7] In addition, dyspnoea, pain, inability to cope at home and an altered level of consciousness were the most important reasons for the hospitalisation of lung-cancer patients.[8]

As previous studies of the reasons for hospitalisation only included lung cancer patients or patients for whom an out-of-hours GP was called, more information was needed on the general group of patients who died non-suddenly. In addition, up to now no information has been available on what occurred before or during hospitalisation, such as who initiated the hospitalisation, what the prognosis was just before hospitalisation and what kind of treatments the patient received. It is important to look in more detail at the patients who are hospitalised and the characteristics of the final hospitalisation in order to understand more about hospitalisations at the end of life. This additional information might give more insight into whether hospitalisations could be avoided. This is relevant since most patients prefer to remain at home at the end of life.[3-5] In addition, hospitalisation can cause distress in patients and diminished continuity of care.[9] Therefore the aim of this study is to explore the reasons for and characteristics of the last hospitalisation in the final three months of life for patients who died non-suddenly. We compare cancer patients with non-cancer patients since it is known that the cancer disease trajectory at the end of life differs from non-cancer disease trajectories.[10,11]

Methods

Design

In 2011, a nationwide retrospective cross-sectional survey with a written questionnaire was conducted among Dutch GPs. In the questionnaire, we asked the GPs to recall their last deceased adult patient in the past year whose death was non-sudden and who was hospitalised in the last three months of life. Hospitalisation was defined as staying in a hospital for at least one night.

Study population

A random sample of 1200 GPs was selected from the population of 8896 registered GPs in the Dutch "Medical Address book" of 2010. Respondents had to be working as a GP in a GP practice at the time of data collection. Of the 1200 GPs in the sample, 150 were not working as a GP when the questionnaire was sent and 100 did not have patients who met the criteria. This resulted in 950 eligible GPs, of whom 322 filled in the questionnaire (34%). In total, five GPs were excluded because they had not filled out the core questions about the reasons for hospitalisation and/or cause of death. This gave a net response of 317 questionnaires.

In the Netherlands, GPs are responsible for palliative-care patients living at home, in homes for the elderly and in inpatient hospice care, but not for patients being cared for in a nursing home. To support GPs, specialised palliative consultation teams in all Dutch regions are available.

Measurements

The written questionnaires were developed using relevant literature[1,2,7,8] and open interviews with five physicians. A draft of the questionnaire was tested among 14 GPs. Their comments were incorporated in the final version of the questionnaire. The questionnaire included closed questions about the patient's age, main treatment goal, prognosis just before hospitalisation, place of death, all diseases of the patient, the cause of death and the number of hospitalisations in the last three months of life. The questionnaire also included one open question about the most important reason for the last hospitalisation. In addition, the characteristics of the last hospitalisation were asked in closed questions about the person who initiated the last hospitalisation, whether an acute episode and/or a diagnostic goal played a role in hospitalisation and the timing and duration of the last hospitalisation. There were also closed questions asking what treatments the patient received in the last three months of life, followed by an open question asking what treatments the patient received during the last hospitalisation.

Analyses

Analyses were performed for patients who died of cancer (n=205) and patients who died of a non-cancer disease (n=112). The most important reasons for hospitalisation were categorised into treatment, diagnostic, symptoms/complaints and social reasons. The symptoms/complaints given as reasons for hospitalisation were labelled in accordance with the main categories and subcategories of the International Classification of Primary Care (ICPC-2).[12]
Descriptive statistics were performed using SPSS 20. A Chi-square test or Fisher's exact test (for low numbers of observations) was used to assess the significance of differences between patients who died of cancer and patients who died of a non-cancer disease.

Results

Characteristics of GPs and patients hospitalised in the final three months of life

The mean age of the GPs (n=317) was 49, with a range from 31 to 64, 55% were male, 6% of GPs completed specialised education in palliative care and 46% worked in a highly urban environment.

Of all patients who died non-suddenly and who were hospitalised in the final three months of life, 31% were 80 years or older, 57% were male, 51% had multimorbidity and 32% died in hospital. Before hospitalisation, the main treatment goal for 80% of all patients was palliation or life prolonging and 40% had a predicted life expectancy of a few weeks or less (table 1). Cancer patients were significantly more likely than non-cancer patients to be aged less than 80 (81% versus 47%) and had a shorter life expectancy before hospitalisation. In addition, cancer patients were significantly less likely to have multimorbidity (39% versus 73%), were less likely to have a curative treatment goal before hospitalisation (6% versus 22%) and were less likely to die in hospital (22% versus 49%) than non-cancer patients. In all, 6% of patients died in an intensive care unit (not in table).

Table 1. Characteristics of hospitalised patients in the final three months of life and differences between patients who died of cancer and patients who died of a non-cancer disease (n=317)

	Total	Died of cancer* (n=205)	Died of non-cancer disease** (n=112)	
	%	%	%	*P* value
Age				**<0.001**
<65	30	41	10	
65-79	39	40	37	
≥80	31	19	54	
Gender				
Male	57	55	60	0.399
Multimorbidity				
Two diseases	28	23	37	**0.012**
Three or more diseases	23	16	36	**<0.001**
Main treatment aim before the last hospitalisation				
Diagnosis was unknown	9	8	12	0.292
Palliation	57	60	51	0.121
Life prolonging	23	26	16	**0.040**
Cure	11	6	22	**<0.001**
Prognosis before the last hospitalisation				**<0.001**
A few days	7	8	6	
A few weeks	33	42	16	
A few months	44	41	49	
A few years	10	3	22	
Cure expected	3	2	5	
Unknown	4	4	2	
Place of death				
Hospital	32	22	49	**<0.001**
Number of hospitalisations in the final three months of life				**0.018**
1	54	51	61	
2	26	25	30	
>2	20	25	12	

* Types of cancer: gastroenterological (33%), lung (31%), prostate (10%), breast (6%) or other (21%)
** Types of non-cancer diseases: cardiovascular (43%), respiratory (30%),
old age/dementia/deterioration (8%), stroke (6%), kidney disease (5%) or other diseases (8%)

Reasons for the last hospitalisation

A total of 71 different most important reasons for the last hospitalisation were reported by the GPs . Two reasons were given for 18% of patients and three reasons for 6% as the most important for the last hospitalisation (not in table). The reasons were categorised into symptoms/complaints (85%), treatment (10%), diagnostic (5%) and social reasons (4%) (table 2). Of all patients most common reasons for hospitalisation were respiratory symptoms (31%), digestive symptoms (17%) and cardiovascular symptoms (17%). Cancer patients were significantly more likely to be hospitalised because of digestive symptoms (22% versus 7%), such as ileus, and for pain in general (9% versus 1%) compared with non-cancer patients. In non–cancer patients, the most frequent reasons for hospitalisation were respiratory symptoms (48% versus 21% for cancer patients), such as dyspnoea and pneumonia, and cardiovascular complaints (29% versus 6%), such as heart failure.

Table 2. Most important reasons for the last hospitalisation in the final three months of life according to the GP and differences between cancer and non-cancer patients (n=317)

Reasons for hospitalisation*	**Total %**	**Died of cancer (n=205) %**	**Died of non-cancer disease (n=112) %**	***P* value**
TREATMENT	10	13	3	**0.002**
Chemotherapy	3	4	0	0.029
Other treatment reasons	7	9	3	0.037
DIAGNOSTICS	5	8	1	**0.009**
SYMPTOMS/COMPLAINTS**	85	78	97	**<0.001**
Respiratory	31	21	48	**<0.001**
Dyspnoea	24	16	39	**<0.001**
Pneumonia	6	3	13	**0.001**
Respiratory, other	3	3	3	0.720
Digestive	17	22	7	**0.001**
Ileus	5	8	0	**0.002**
Abdominal pain	4	4	5	1
Vomiting/nausea	3	4	1	0.105
Digestive bleeding (melaena, stomach or rectal bleeding)	3	3	2	0.717
Digestive, other	3	3	1	0.268
Cardiovascular	14	6	29	**<0.001**
Heart failure	10	3	21	**<0.001**
Pulmonary or deep venous embolism	2	2	3	0.669
Cerebrovascular accident	2	1	4	0.190
Cardiovascular, other	1	1	2	0.286
Endocrine, metabolic or nutritional	8	7	9	0.611
Dehydration	3	2	5	0.175
Ascites	3	3	1	0.268
Endocrine, metabolic or nutritional, Other	2	2	3	0.701
General				
Pain	6	9	1	**0.005**
Weakness/ malaise	5	6	3	0.203
Deterioration	4	3	5	0.393
Fever	2	3	0	0.093

Table 2. (continued)

Reasons for hospitalisation*		Total %	Died of cancer (n=205) %	Died of non-cancer disease (n=112) %	*P* value
Psychological		4	3	5	**0.393**
Delirium		3	2	5	0.332
Psychological, other		1	1	1	1
Musculoskeletal:	Fracture	4	3	5	0.760
Urinary		5	4	6	0.470
Neurological		4	6	2	0.150
Blood:	Blood problems (e.g. anaemia)	2	2	2	1
Social:	Family reasons	4	4	3	0.752

* Reasons are presented in the table if they were noted in total for more than 2% of the sample

**Categorised according the International Classification of Primary Care (ICPC)

Characteristics of the last hospitalisation

In general, hospitalisation was most likely to be initiated by the patient's own GP (46%) (table 3). Even in acute episodes, the patient's own GP was involved for 44% of patients (not in table). The hospitalisation of cancer patients was significantly less likely to be initiated by a locum (23% versus 38%) and more likely to be initiated by the patient and/or family (13% versus 5%) or the medical specialist (17% versus 6%) compared with non-cancer patients. An acute episode played a role in the hospitalisation of 73% of all patients and a diagnostic goal played a role in the hospitalisation of 44% of patients. Patients experiencing an acute episode were significantly more likely to have respiratory symptoms (34% versus 21%) and cardiovascular symptoms (17% versus 7%) than patients in non acute episodes (not in table). In all, 18% of patients received only pharmacological treatment, excluding chemotherapy, or no treatment at all in the hospital; furthermore, no diagnostic goal played a role either in the hospitalisation of these patients (not in table). Cancer patients were significantly more likely to receive medication for pain relief, chemotherapy, radiotherapy and/or stent implementation and non-cancer patients were significantly more likely to receive pharmaceutical treatment, infusion therapy, antibiotics, oxygen delivery, diuretics and medication change. One third of all patients were hospitalised in the last week before death. A significantly higher proportion of cancer patients had a short stay in hospital of 1-2 days (33% versus 15% of non-cancer patients).

Table 3. Characteristics of the last hospitalisation in the final three months of life and differences between patients who died of cancer and patients who died of non-cancer disease (n=317)

Characteristics of hospitalisation	**Total** %	**Died of cancer (n=205)** %	**Died of non-cancer disease (n=112)** %	***P* value**
Person who initiated hospitalisation				**0.001**
Patient's own GP	46	46	46	
GP locum	29	23	38	
Patient and/or family	10	13	5	
Medical specialist	13	17	6	
Other person	3	2	5	
Aspects that played a role in hospitalisation				
Acute episode	73	70	77	0.131
Diagnostic goal	44	46	38	0.172
Treatment received in hospital*	84	78	95	**<0.001**
Pharmaceutical treatment	54	44	74	**<0.001**
Antibiotics	18	12	29	**<0.001**
Medication change	16	12	22	**0.038**
Oxygen delivery	16	10	26	**0.001**
Diuretics	9	1	24	**<0.001**
Pain medication	8	10	4	**0.047**
Chemotherapy	5	8	0	**0.002**
Palliative sedation	3	4	2	0.503
Non-pharmaceutical treatment	61	63	58	0.398
Infusion therapy	28	23	36	**0.025**
Surgical treatment	8	9	6	0.314
Blood transfusion	7	8	4	0.161
Tube feeding	4	6	2	0.231
Radiotherapy	4	6	0	**0.010**
Urinary catheter	4	5	3	0.757
Syringe pump	4	3	5	0.520
Ascites puncture	3	5	1	0.173
Stent implantation	3	5	0	0.030
Pleural puncture	3	4	2	0.723
Gastric drainage	3	4	1	0.172
Other treatment	13	11	15	0.397

Table 3. (continued)

Characteristics of hospitalisation	Total %	Died of cancer (n=205) %	Died of non-cancer disease (n=112) %	*P* value
Time of hospitalisation				0.469
1-2 days before death	11	9	14	
3-6 days before death	19	17	22	
1-2 weeks before death	24	25	24	
3-4 weeks before death	17	17	16	
> 4 weeks before death	29	32	25	
Length of hospitalisation				**0.001**
1-2 days	27	33	15	
3-6 days	32	33	30	
1-2 weeks	27	21	38	
3-4 weeks	10	10	11	
> 4 weeks	4	4	6	

*More than one answer could be given

Discussion

Summary

Of all patients who died non-suddenly and who were hospitalised in the last three months of life, 65% had cancer. Symptoms or complaints were mentioned in 85% of cases as the most important reason for hospitalisation, with respiratory, digestive and cardiovascular symptoms being the most common. In about half of the cases, the patient's own GP initiated the hospitalisation and in 73% of patients experienced an acute episode before hospitalisation. Compared to non-cancer patients, cancer patients were significantly more likely to be aged less than 80, were more likely to have digestive symptoms as an important reason for hospitalisation, were more likely to have a short stay of less than three days in the hospital and were less likely to die in hospital. Non-cancer patients were more likely to have multimorbidity, were more likely to have respiratory symptoms and/or cardiovascular problems as the reason for hospitalisation, were more likely to have a curative treatment goal before the last hospitalisation and were more likely to receive antibiotics, oxygen and/or diuretics than cancer patients.

Strengths and limitations

A strength of this study is that data are included from both cancer patients and non-cancer patients at the end of life of a GP practice. This study provides new insights into the reasons for hospitalisation and the characteristics of hospitalisations. Hence it gives indications for GPs to anticipate most common symptoms in cancer and non-cancer patients.

A limitation of the study is the low response rate. However, the age, gender and level of practice urbanisation of our study population do not differ from that of the general Dutch population of GPs.[13,14] In addition, in our research more respondents completed a specialised education in palliatieve care (6%) than in the general population of Dutch GPs. However, for reasons and avoidability, we found no significant differences between the educated group and the non-educated group. Therefore, we think that the low respons rate of GPs has little or no effect on the generalisability.

A possible limitation of the study is that GPs were not fully informed about their patient's situation during the hospitalisation and all the treatments given, which may have led to an underestimation of hospital treatment.

Palliative care

The present study shows that a need for symptom relief is most likely to be the most important reason for hospitalisation in both cancer and non-cancer patients. As improving the quality of life through symptom relief is an important goal of palliative care, it seems that many of the hospitalisations at the end of life fit in with a palliative care approach.[15] This notion is further supported by the type of treatments patients received in hospital, such as antibiotics, oxygen delivery and diuretics to treat dyspnoea, pneumonia or heart failure, and by our finding that cure was still the main treatment goal for only 11% of patients before the last hospitalisation. However, it can be questioned whether the hospitalisations were necessary in all cases. Other studies indicate inappropriate hospitalisations or aggressive care at the end of life.[8,16,17] Walsh *et al.*[18] suggest that these conditions could often be managed outside the hospital, particularly in the case of patients with pneumonia, congestive heart failure, urinary tract infections, dehydration and chronic obstructive pulmonary disease. In addition, low levels of hospitalisation for the population as a whole are considered to be a quality indicator of good palliative care.[19]

An explanation for patients being hospitalised rather than staying at home in the last phase of life might be found in our finding that hospitalisation took place in an acute episode in 73% of cases. Acute episodes can be expected at the end of life and therefore it is recommended to anticipate patients' needs.[20] Ways of anticipating that can be successful in reducing hospitalisations are the availability of appropriate “as needed” medication to be used in acute episodes at home,[21] information transfer from GPs to the out-of-hours general practice and the monitoring of symptoms and timely discussions with the patient/family about their preferences and what can happen at the end of life.[22-24]

Illness trajectories

This study compared the hospitalisation of cancer patients with that of non-cancer patients. It enables us to relate our results to the different illness trajectories described by Lynn *et al.*[10] and Murray *et al.*[11] Firstly, they distinguish a common cancer end-of-life trajectory characterised by a period of relatively good functioning with a rapid and reasonably predictable decline in clinical status and a foreseen death. Secondly, two trajectories were distinguished for non-cancer patients: a trajectory for patients with organ failure such as COPD and heart failure, and a trajectory for frail patients, such as dementia patients. Both illness trajectories are characterised by a slow functional decline, which may end in an acute event. The acute event for patients with an organ disease often concerns an acute exacerbation. For frail patients, the acute event often concerns pneumonia.[10,11] With these common illness trajectories in mind, one would expect that compared with non-cancer patients, cancer patients would be less likely to have a curative treatment goal. In relation to this, one would also expect that the approaching death is more likely to be foreseen in cancer patients. Our results do indeed point in this direction: 6% of the cancer patients had a curative treatment goal versus 22% of the non-cancer patients, and at the time of the last hospitalisation the predicted life expectancy was a few weeks or less for 50% of cancer patients as opposed to 22% of non-cancer patients. The fact that the approach of death is more difficult to foresee in non-cancer patients may hamper a timely start to palliative care in this group. Other studies also indicate that it is difficult to identify when palliative care starts for non-cancer patients.[25-27] Therefore, more education and research is needed to identify when palliative care starts in non-cancer patients. With the more predictable cancer trajectory in mind, one would also expect that hospitalisation in cancer patients would be less likely to involve an acute episode. However, we did not find this in our study, suggesting the need for better anticipation in all patients in the last phase of life.

Implications for research and practice

It is important for professionals to understand the main reasons and characteristics of hospitalisations at the end of life and the differences between cancer and non-cancer patients in order to reduce hospitalisations at the end of life. Anticipating hospitalisations requires monitoring of common symptoms, such as respiratory problems in all patients and digestive problems in cancer patients. In addition, it is important to have timely discussions with the patient and family about the preferences for hospital or home treatment in the case of acute episodes. Further studies are needed on effective ways to anticipate evolving and increasing symptoms early in the disease trajectory to avoid acute episodes and hence reduce hospitalisations at the end of life.

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Chapter 3

End-of-life hospital referrals by out-of-hours general practitioners: a retrospective chart study

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Abstract

Background

Many patients are transferred from home to hospital during the final phase of life and the majority die in hospital. The aim of the study is to explore hospital referrals of palliative care patients for whom an out-of-hours general practitioner was called.

Methods

A retrospective descriptive chart study was conducted covering a one-year period (1/Nov/2005 to 1/Nov/2006) in all eight out-of-hours GP co-operatives in the Amsterdam region (Netherlands). All symptoms, sociodemographic and medical characteristics were recorded in 529 charts for palliative care patients. Multivariate logistic regression analysis was performed to identify the variables associated with hospital referrals at the end of life.

Results

In all, 13% of all palliative care patients for whom an out-of-hours general practitioner was called were referred to hospital. Palliative care patients with cancer (OR 5,1), cardiovascular problems (OR 8,3), digestive problems (OR 2,5) and endocrine, metabolic and nutritional (EMN) problems (OR 2,5) had a significantly higher chance of being referred. Patients receiving professional nursing care (OR 0,2) and patients for whom their own general practitioner had transferred information to the out-of-hours cooperative (OR 0,4) had a significantly lower chance of hospital referral. The most frequent reasons for hospital referral, as noted by the out-of-hours general practitioner, were digestive (30%), EMN (19%) and respiratory (17%) problems.

Conclusion

Whilst acknowledging that an out-of-hours hospital referral can be the most desirable option in some situations, this study provides suggestions for avoiding undesirable hospital referrals by out-of-hours general practitioners at the end of life. These include anticipating digestive, EMN, respiratory and cardiovascular symptoms in palliative care patients.

Introduction

Many patients are transferred between care settings during the final phase of life.[1-4] In the final months of life, the most frequent trajectory of patients who die a non-sudden death is from home to hospital. The proportion following this trajectory ranges from 36 to 40% in the final three months of life in the Netherlands and Belgium to 68% in the final six months of life in Canada. The majority of patients who are transferred from home to hospital later die in hospital.[5-7] Two factors associated with hospital death are having spent at least one night in a hospital and the number of hospital admissions during the final year of life.[8-9]

Hospital transfer, time spent in hospital at the end of life and hospital deaths are mentioned in the literature as poor end-of-life outcome indicators.[10-12] Although some end-of-life hospital transfers are necessary and could benefit the patient, most patients prefer to receive care and die at home, and most families evaluate staying at home as a desirable palliative pathway.[13-15]

General practitioners (GPs) are key professionals in providing continuity of care at the end of life.[16.17] However, over the last two decades, the 24-hour availability of GPs has changed, with out-of-hours GP co-operatives at a greater distance and patients being more likely to receive care from a locum[18.]19 these changes could reduce the continuity of care.[20,21] Proper information transfer from the GP to the out-of-hours GP is an essential factor in optimizing continuity of care. In the Netherlands, 82% of GPs reported that they transferred information about terminally ill patients to out-of-hours GPs.[21] However, various studies of chart analyses of palliative care patients for whom an out-of-hours GP was called have shown that information from the patients' own GP was available only for a minority.[22-25]

In a study of patients referred to a palliative care programme, it was found that symptoms other than pain increase the number of transfers to in-patient care at the end of life.[2] However, no details were given about the type of symptoms. Other factors in addition to symptoms have also been found to increase the likelihood of hospital transfer at the end of life. Studies of general practices (not specifically limited to out-of-hours practices) show that age, gender, multiple morbidity, infections, respiratory problems, cardiovascular problems, a palliative treatment goal, GPs' knowledge of patients' wishes about the place of death and palliative treatment by the GP are all related to hospital transfers in the final three months of life.[6,26]

The aim of our study was to explore hospital referrals of palliative care patients for whom an out-of-hours GP was called, in recognition of the fact that hospital transfers at the end of life can be undesirable for patients and their families and that the out-of-hours service might be a critical period for these referrals. The research questions were as follows. What is the incidence of hospital referrals of palliative care patients by out-of-hours general practices? What sociodemographic and medical characteristics and what symptoms presented by palliative care patients as noted by an out-of-hours GP are associated with end-of-life hospital referrals? What reasons for referrals from home to hospital are noted by the out-of-hours GP?

Methods

Design

A retrospective descriptive chart study was conducted looking at a one-year period (1/Nov/2005 to 1/Nov/2006) in all eight out-of-hours GP co-operatives in the Amsterdam region (Netherlands).

Study population and setting

All 424 GPs in the Amsterdam region with local practices are also required to work shifts as locums for the eight out-of-hours GP cooperatives that serve the 800,000 inhabitants of Amsterdam. Patients who need help during the out-of-hours period can call a special number. Each patient call is noted in an electronic database known as Callmanager.

In the Netherlands, the GP is responsible for patients living at home and in homes for the elderly. Patients living at home have access to professional home care nurses, provided if there is a medical indication, while professional nurses are available 24 hours a day in homes for the elderly.

The Ethics Board of the VU University Medical Center, Amsterdam, was informed about the study, and they decided that the study did not require a formal ethical review.

Patient calls

The total number of patient calls to the out-of-hours GP co-operatives during the one-year study period was 137,828. The records of all phone calls were screened electronically. Palliative care patients were identified by means of a search within the text for the words "palliative", "terminal", "cancer", "carcinoma", "inoperable", "opioid" and "fentanyl". The content of the 2304 records identified this way was subsequently examined by a GP with extensive experience in palliative care (BS). He included all contacts in which any mention was made of palliative care needs, palliative medication, remarks about terminal illness etc. This resulted in a list of calls for 553 different palliative care patients. The sensitivity of the search was checked by comparing the electronic search results with a manual search of data for all calls over a one-month period. This did not produce any new calls about palliative care patients and it was therefore decided that the manual search should be stopped.[24] Next, patients were excluded who died just before or during the locum's visit or who were staying in a hospice. This left a total of 529 patients for whom an out-of-hours GP co-operative was called (Fig. 1).

Recording and analysis of the symptoms and care aspects

One of the authors (BS) analysed the charts of palliative care patients for whom the out-of-hours GP co-operative was called (for a different paper about GP information transfer). For each patient we had one chart; for patients who had multiple contacts with the GP co-operative, only the final contact chart was included. The author recorded gender, age, type of residence (patient's home or home for the elderly), disease, a single main reason for the encounter, terminal status and hospital referral. Those results have been published elsewhere.[24] This paper is focusing on hospital referrals and this paper's first author (MDK) therefore additionally recorded all the symptoms that were noted in the charts, all medical aspects and the reasons for hospital referral, and discussed this with the third author (BS). The symptoms were noted without interpreting possible mutual or causal relationships. We used the term hospital referral instead of hospital transfer because it is not clear from the charts whether the patient actually went to hospital.

Locums make a short report of the patient calls in a structured 'SOEP' registration system. The subjective reasons for the encounter are noted under S and the O contains the locum's observations. The S and O categories provided the following variables: symptoms, family aspects, use of professional nursing care, patients' wishes and medical aspects. The E category contains the evaluation of the situation from the locum's perspective and also gives the reason for hospital referral. Finally, the plan - for instance the hospital referral - is noted in the P category. The symptoms were labelled in accordance with the main categories and subcategories of the International Classification of Primary

Care (ICPC-2). If they were not described in the ICPC-2, they were classified according to the International Classification of Diseases (ICD10).[27,28] Being terminally ill, the availability of family and receiving professional nursing care were counted as variables if the GP explicitly noted this in the chart. The symptoms presented in the tables are those that were noted for more than 5% of either of the two groups (patients with hospital referral and patients without hospital referral).

Analysis

A T-test was used to compare the age and number of symptoms of referred patients with that of patients who had no hospital referral. A chi-squared test or Fisher's exact test was used to assess the significance of differences in other sociodemographic and medical characteristics and in symptoms.

Multivariate logistic regression analysis was performed in order to identify the variables associated with hospital referral. First, univariate logistic regression was performed for each of the sociodemographic and medical characteristics (if noted for more than 5% of patients) and main categories of symptoms individually. All the significant variables ($P<0.05$) were then entered in a stepwise backward multivariate logistic regression analysis (*P value* for removal > 0.05). Because of the large overlap between place of residence (home for the elderly) and receiving professional nursing care, we only included 'receiving professional nursing care' in the multivariate analysis.

Results

Patient characteristics

In total, 13% of all palliative care patients for whom an out-of-hours GP co-operative was called were referred to hospital. Table 1 shows that 53% of all patients were male, the mean age was 73, 84% lived at home and 76% had cancer. Patients who were referred to hospital were significantly more likely to live at home (96% versus 82%), to have cancer (94% versus 73%) and to be receiving chemotherapy (12% versus 2%). In addition, patients for whom hospitalisation was already planned within three days (10% versus 1%) and patients for whom a hospital specialist had already been contacted (9% versus 1%) were significantly more likely to be referred to hospital. Patients were significantly less likely to be referred to hospital if the patient was terminally ill according to the locum (75% versus 54%), if the patient was receiving professional nursing care (for the patients not living in a home for elderly: 30% versus 10%) or if information was available from the patients' own GP (27% versus 9%).

Table 1. Sociodemographic and medical characteristics of palliative care patients as noted by an out-of-hours GP (N=529)

	Total n=529 %	**Referral** n=68 %	**No Referral** n=461 %	*P* value
Gender				
Male	53	47	54	0.283
Age (years)				
Mean (SD)	73 (SD 14)	75 (SD 13)	73 (SD14)	0.297**
≥ 75	50	52	50	0.795
Residence				
Home	84	96	82	**0.006**
Home for the elderly	16	4	18	
Disease				
Cancer	76	94	73	**<0.001**
Heart failure	4	4	4	0.743*
COPD	3	0	3	0.234*
Other diseases	18	1	20	**<0.001**
Terminal status				
Terminally ill	73	54	75	**<0.001**
Family				
Family available	59	62	58	0.594
Family burden	7	9	7	0.455*
Receiving professional nursing care				
Receiving professional nursing care	41	12	46	**<0.001**
Patients wish				
Patients' wish to stay at home	10	12	9	0.520
Medical aspects				
Information transfer by patients' GP	24	9	27	**0.002**
Patient was receiving chemotherapy	4	12	2	**0.001***
Hospitalisation was already planned within three days	2	10	1	**<0.001***
Patient or family had already contacted a hospital specialist	2	9	1	**<0.001***

*Fisher Exact Test (2-sided)

** T-test

Symptoms

In total, 39 different symptoms were noted in the SOEP registration system. Pain (42%), dyspnoea (26%), agitation/confusion (19%), loss of appetite (19%), drowsiness (14%) and nausea/vomiting (16%) were the symptoms most commonly recorded (table 2). Patients who were referred to hospital had significantly more symptoms (a mean of 3 versus a mean of 2) and were more likely to have digestive problems (53% versus 26%), endocrine, metabolic or nutrition (EMN) problems (46% versus 22%) or cardiovascular problems (13% versus 4%) than patients who were not referred. Looking in greater detail, the patients referred were more likely to have problems with nausea/vomiting (41% versus 12%), loss of appetite (35% versus 17%), dehydration (16% versus 3%), cachexia (12% versus 5%), pulmonary or deep venous thrombosis (7% versus 1%) and ileus (7% versus 2%) (table 2).

Table 2. Symptoms as noted by an out-of-hours GP (N=529) (the S and O in the SOEP registration)

Main ICPC category Symptom	**Total** n=529 %	**Referral** n=68 %	**No Referral** n=461 %	*P* value
General	**48**	**52**	**48**	0.564
Pain	42	46	41	0.495
Fever ≥38	5	6	5	0.762*
Other	3	4	3	0.446*
Digestive	**30**	**53**	**26**	**<0.001**
Vomiting/ nausea	16	41	12	**<0.001**
Swallowing problems	8	6	8	0.575
Diarrhoea	3	6	3	0.137*
Ileus	3	7	2	**0.017***
Ascites	2	6	2	0.056*
Other	6	4	6	0.785*
Respiratory	**26**	**31**	**25**	0.335
Dyspnoea	26	31	25	0.296
Other	1	2	1	0.564*
Endocrine, metabolic or nutritional	**25**	**46**	**22**	**<0.001**
Loss of appetite	19	35	17	**<0.001**
Cachexia	6	12	5	**0.042***
Dehydration	4	16	3	**<0.001***
Other	2	3	2	0.625*
Psychological	**24**	**19**	**24**	0.444
Agitation and confusion	19	15	19	0.385
Other	8	4	9	0.249
Neurological	**16**	**9**	**17**	0.088
Drowsiness	15	7	16	0.055
Other	1	3	1	0.174*
Urological	**8**	**9**	**8**	0.812
Cardiovascular	**5**	**13**	**4**	**0.001**
Pulmonary or deep venous embolism	2	7	1	**0.005***
Other	2	6	2	0.056*
Skin problems	**5**	**7**	**5**	0.387
Number of Symptoms (mean, SD)	**2.1 (SD 1.4)**	**3,0 (SD 1,6)**	**2,0 (SD 1.3)**	**0.038****
Patients with >2 symptoms	32	56	28	**<0.001**

*Fisher Exact Test (2-sided)

** T-test

Associations with hospital referral

Cancer, terminal illness, receiving nursing care, information transfer, digestive problems, EMN problems, cardiovascular problems and patients with more than two symptoms were significantly related to out-of-hours hospital referral in the univariate logistic regression analysis (*P*<0.05) and were therefore included in the multivariate logistic regression analysis. Six variables remained significant (table 3). Patients with cardiovascular problems (OR 8.3), cancer (OR 5.1), digestive problems (OR 2.5) and EMN problems (OR 2.5) were more likely to be referred to hospital. Patients who received professional nursing care (OR 0.2) and for whom their own GP had transferred information (OR 0.4) were less likely to be referred to hospital (table 3).

Table 3. Association with end-of-life hospital referral*

	OR (95% CI)
Cancer	5.1 (1.7-15.8)
Cardiovascular problems	8.3 (2.9-24,0)
Digestive problems	2.5 (1.4-4.6)
Endocrine, metabolic, and nutritional problems	2.5 (1.4-4.5)
Receiving professional nursing care	0.2 (0.1-0.5)
Information transfer by GP	0.4 (0.2-1.0)

*Stepwise backward multivariate logistic regression analysis
The model demonstrated good calibration performance according to the Hosmer-Lemeshow goodness-of-fit test (*P* = 0.97) and a discriminatory ability of the area under the curve (AUC) of 0.83.

Reasons for hospital referral

Twenty different symptoms and two other problems were noted as a reason for hospital referral from the perspective of the locum (table 4). Digestive problems (31%), EMN problems (19%) and respiratory problems (18%) were the most common. At a more detailed level, vomiting (16%), dehydration (16%) and pneumonia/pleuritis (13%) were the reasons most often given for hospital referral. Two or three symptoms were mentioned for eleven patients and the family burden was mentioned for three patients (table 4).

Table 4. Reasons for hospital referral as noted by the out-of-hours GP (the E in the SOEP registration N=68)

		N	%
Digestive		**21**	**30.9**
	Vomiting (incl. haematemesis)	11	16.2
	Ileus	4	5.9
	Ascites	3	4.4
	Rectal bleeding	2	2.9
	Peritonitis	1	1.5
Endocrine, metabolic and nutritional		**13**	**19.1**
	Dehydration	11	16.2
	Hyperglycaemia	2	2.9
Respiratory		**12**	**17.6**
	Pneumonia/pleuritis	9	13.2
	Dyspnoea	3	4.4
Cardiovascular		**8**	**11.8**
	Cardiac	4	5.9
	Deep venous thrombosis (feet)	3	4.4
	Pulmonary embolism	1	1.5
General		**7**	**10.3**
	Pain	5	7.4
	Weakness	1	1.5
	Fever	1	1.5
Other symptoms		**14**	**20.6**
	Epilepsy	6	8.8
	Anuria	4	5.9
	Confusion/delirium	3	4.4
	Fracture	1	1.5
Other aspects			
	Family burden or no family	6	8.8
	Diagnosis in the hospital	1	1.5

Discussion

Examining 529 records of palliative care patients from out-of-hours GP co-operatives in the Amsterdam region, we found that 13% of palliative care patients were referred to a hospital. Palliative care patients with cancer, cardiovascular problems, digestive problems and endocrine, metabolic and nutritional (EMN) problems had a significantly higher chance of being referred after the out-of-hours consultation. Patients receiving professional nursing care and patients for whom their own GP had transferred information to the out-of-hours co-operative had a significantly lower chance of being referred after calling an out-of-hours GP. The reasons most commonly given for hospital referral were digestive problems, EMN problems and respiratory problems. The most common digestive problem was vomiting and the EMN problem noted most often was dehydration.

Sociodemographic and medical characteristics

The multivariate analyses showed that palliative care patients had a lower chance of hospital referral in the out-of-hours period if they were receiving nursing care. Other studies have also found that patients receiving professional nursing care at the end of life are more likely to stay at home.[29,30] It is reasonable to assume that the nurse will in many cases know the patient's situation and the care options at home better than a locum and will consequently be able to propose alternative 'solutions' to hospitalisation. It therefore seems that nurses may considered as one of the 'gatekeepers' of out-of-hours hospitalisation of palliative care patients. In addition to nursing involvement, it was also found that patients were less likely to be referred to hospital if their GP had transferred information to the locum. However, we also found that information from the patients' own GP was only available for a minority of patients during the out-of-hours period. This lack of information transfer has also been noted in other studies looking at out-of-hours practices.[22,23,25]

Symptom*s*

Although 42% of the patients in this study were found to be in pain, this was often not the reason noted for out-of-hours hospital referrals. Symptoms such as digestive, EMN and respiratory problems were noted down more frequently as reason for referral (table 4). This suggests that out-of-hours GPs may be better at handling pain in palliative care patients than other symptoms.

As in our study, studies concerning out-of-hours care but not specifically focusing on palliative care patients also found that digestive problems are frequently recorded as a symptom.[30,31] We found digestive problems to be positively related to hospital referrals as well. About half of the referred patients in our study had digestive problems and 78% of these patients had problems with nausea and/or vomiting. Nausea/vomiting can have several causes, such as hypercalcaemia, obstipation, ascites, ileus or intracranial pressure.[32] The complexity of diagnosing or treating this might be a reason for hospital referral. EMN problems were not found to be noted frequently in other studies,[30,31] but in our study it was noted as a problem for 25% of the patients. EMN problems were also found to be significantly related to hospital referrals in our study. In the EMN category, 83% of the problems were caused by nutritional problems (loss of appetite, dehydration and cachexia). It is neither immediately apparent why an out-of-hours GP co-operative might be called for nutritional problems nor why out-of-hours GPs might consider this to be an acute reason for hospital referral.

Strengths and limitations of the study

The strength of the study is the detailed information about sociodemographic and medical characteristics and symptoms of patients for whom an out-of-hours GP was called. A limitation of the study is that data was collected six years ago; however, there is no indication that GP services have changed substantially in the intervening years. Another limitation of the study is that problems were not measured systematically, for instance using a scoring list. Instead, the study used the reported problems as noted in the charts, which means that patients could have had additional problems. However, it is assumed that the problems noted were those causing the most distress. Furthermore, in our study it is possible that not all palliative care patients were detected by the electronic search strategy, although it should be noted that a manual search of a subset of the data did not uncover new patients. Additionally, it is not known whether the referred patients were indeed transferred to hospital after referral. Finally, we do not know if the hospital referrals found in our study could have been avoided or were undesirable.

Conclusion

The results of this study provide detailed information about associations with hospital referrals, and the reasons for hospital referral outside standard hours. Whilst acknowledging that hospital referral can be the most desirable option in some situations, this study provides suggestions for avoiding undesirable hospital referrals at the end of life. Since it is not known how many of the hospital referrals were potentially avoidable and/or undesirable, further research should be done in this area. In order to anticipate potentially undesirable hospital transfers in out-of-hours periods, patients' GPs could decide to provide information to out-of-hours GPs at an early stage, arrange for a nurse at home and be alert to digestive, nutritional and cardiovascular symptoms.

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Chapter 4

Burden for family carers at the end of life; a mixed-method study of the perspectives of family carers and GPs

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Abstract

Background
Since many patients spend most of the time at home at the end of life, this may affect the burden for family carers and constitute a risk factor for the patients' hospitalisation. This study aimed to explore family carers' burden in the final three months of the patient's life, from the perspective of both carers and general practitioners (GPs), and to assess whether family burden, as defined by the GP, is associated with hospitalisation.

Methods
A cross-sectional nationwide survey among GPs and family carers was performed. Participants were 194 GPs and 74 family carers of patients who died non-suddenly. Additionally, in-depth interviews were conducted with 18 family carers. For the quantitative analyses descriptive statistics, weighted Kappa and multivariate logistic regression analysis was performed. For the qualitative part thematic analysis was conducted.

Results
The proportion of family carers experiencing a fairly heavy or severe burden increased significantly from 32% (second and third months before death) to 66% (one week before death). Most carers (95%) felt an emotional burden and 29% felt a physical burden in the final week. Three-quarters of carers did not perceive their burden as a problem because caring often felt rewarding. No significant association was found between the characteristics of family caregivers or professional care and the degree of family caregiver burden. Also, there was no significant evidence that patients of family carers for whom the GP assessed a fairly heavy to severe burden, were more likely to be hospitalised.

Conclusions
The different overall assessment of family carers' burden between GPs and family carers and the increasing emotional and physical burden of family carers towards the end constitute relevant information for GPs that will help them understand and anticipate carers' personal needs.

Introduction

Since many palliative care patients spend most of the time at home at the end of life,[1,2] this may have an impact on the burden for family carers. Family carers may feel different kinds of burden at the end of the patient's life: not just a physical burden, but also an emotional burden.[3-7] Burden has the potential to increase the carer's vulnerability and may be a risk factor for burn-out.[8]
In many countries, the General Practitioner (GP) is the key professional providing palliative care at home.[9-12] A guiding principle in palliative care is that the GP not only gives attention to the patient but also offers information and support to the family.[13,14] GPs usually pay frequent visits to the patient towards the end of life .[15]

At the end of life, many patients experience a functional decline[16,17] which may have impact on burden for family carers. Therefore, it is important to explore how burden develops as the patient approaches death, and how family carers experience this. In addition, different studies found discrepancies in assessment of symptoms or quality in life from the physicians' and family carers' perspectives.[18,19] As a consequence of this, whether the GP assessment agrees with the family carers' self-assessment is of interest in terms of family carers' burden.

Several studies reported that living with relatives, extended family support, the ability of family carers to cope with the patients' illness and low psychological distress among carers are positively associated with home deaths.[20-22] In a study of out-of-hours general practices, family carers' burden was one of the reasons for hospital referral for 9% of palliative care patients who were referred to a hospital,[23] but it is unknown whether carers' burden is associated with hospitalisation at the end of life.

To explore family carers' burden in the final three months of the patient's life, from the perspective of both carers and GPs, to assess whether burden is associated with family carer characteristics, (professional) care and hospitalisation; the following research questions addressed in this paper are 1) What degree of burden and which types of burden do family carers experience during the final three months of a patient's life and does the burden change as the patient approaches death? 2) Is the degree of family carers' burden associated with characteristics of family caregivers and (professional) care? 3) What is the level of agreement between the self-assessment of burden by family

carers and the assessment by GPs? 4) Is the degree of burden, defined and assessed by the GP, associated with hospitalisation in the final week of a patient’s life?
In this study we define a family carer as an unpaid person providing physical, practical and/or emotional care and/or support to a relative or friend.

Methods

Design

We conducted a mixed-method study, using a deductive sequential strategy.[24] Firstly, we conducted a cross-sectional nationwide quantitative survey among GPs and family carers in the Netherlands in 2011. Secondly, we held qualitative interviews among a selection of carers in order to explore the answers given in the quantitative survey in more depth.

Study population

Quantitative study

The present study about family carers’ burden at the end of life is part of a larger study about hospitalisations at the end of life. For this larger study, a random sample of 2000 GPs was selected from 8896 registered GPs in the 2010 Dutch “Medical Address book”. In the questionnaire we asked the GPs to recall the last adult patient who died non-suddenly in the past year. Of the 2000 GPs in the sample, 238 were not working as a GP when they received the questionnaire and 161 had not had a patient who met the inclusion criteria. This resulted in 1601 eligible GPs. 222 GPs (14%) responded to the first mailing; the total response after follow-up mailings was 598 GPs (37%). We only asked the GPs about carers’ burden in the first mailing. Also, it was only in this first mailing that we asked the GPs to send a letter to the patient’s main family carer. In this letter, the carer was invited to participate in the research. In total, 121 GPs sent a letter to the carer. Of the 101 GPs who did not send a letter to the carer, 28 stated that they did not know the carer’s address and 31 considered the questionnaire too burdensome. Of the 121 carers approached, 83 completed the questionnaire. For the present paper we excluded 28 of the 222 GP questionnaires and 9 of the 83 carer questionnaires, since they reported on patients who had not resided at home most of the time in the last three months of life. This left 194 GP questionnaires and 74 carer questionnaires for the present paper.

Qualitative interview study

A total of 28 family carers indicated that they would be willing to participate in the interview study. Based on the questionnaires family carers had filled in, we were able to select purposively 18 of the 28 eligible carers. Purposive selection was based on diversity in degree and type of burden, age, patients' disease and whether or not the patient was hospitalised.

Measurement

Quantitative questionnaire study

The written questionnaires for GPs and family carers were developed using relevant literature [3-7] and open interviews with five doctors and three carers. A draft of the questionnaire was tested on face validity among 14 GPs and six carers. Their comments were incorporated in the final version of the questionnaires.

The family carers' questionnaire consisted of several parts, one of which concerned the burden experienced. Although family carers' burden is often seen as multi-dimensional,[4,6,7] for this study we chose one general question. Family carers were asked "Overall, how burdened did you feel?" in three periods: in the second and third months before the patient's death, in the second to fourth weeks before death and in the final week on a four-point scale ('not/hardly at all', 'somewhat', 'fairly heavy' and 'severe'). After this general question, we asked about two types of burden, distinguishing between an emotional and a physical burden, and whether the burden was perceived as a problem to them. The GP questionnaire included the same general question about the degree of burden experienced by family carers. GPs were also asked if and when the patient was hospitalised. Hospitalisation was defined as staying in a hospital for at least one night.

Qualitative interview study

Of 18 open in-depth interviews, 15 face-to-face interviews were held at the family carer's home and three were conducted by phone. The mean interview time was one hour. The open interviews started with a 'grand tour' question: "Tell me about the situation of your relative in the last six months of life." Answers given in the questionnaire study were used to probe more deeply into this experience; for example, "You filled in that you didn't experience the burden as a problem - can you say more about that?" These open interviews were conducted by an experienced interviewer (MDK) in the first half of 2012.

Analyses

Quantitative questionnaire study

The degree and type of burden experienced by family carers (n=74) were analysed using descriptive statistics with a confidence interval of 95%. A Chi-square test (categorical data) or independent T-test (continuous data) were used to assess the significance of differences between family carers who experienced a high level of burden and family carers who experienced a low level of burden with regard to caregiver and care characteristics. To assess the level of agreement between the GPs' assessment of family carers' burden and the self-assessment of the burden by the family carers, we checked the relationship of the family carer to the patient in the GP questionnaire with that in the corresponding family carer questionnaire. We concluded that nine did not match and they were therefore excluded in this analysis (giving n=65). For these dyads a weighted Kappa was calculated.

A multivariate logistic regression analysis was performed to test the hypothesis that GPs' assessment of family carers' burden is associated with hospitalisation in the final week of life. For this analysis we used the data of all responding GPs and used the GPs' assessment of the family carers' burden in the second to fourth week before the patient's death, so that we are sure the burden already existed before the hospitalisation.

Qualitative interview study

The verbatim transcribed interviews were analysed using qualitative data analysis.[25] The first transcripts were read thoroughly and the first codings were discussed by two researchers experienced in qualitative research (MDK and HP). Then a coding scheme was conceived based on the answers given in the questionnaire study and the new themes we found in the transcripts. Then the coding scheme and interview transcripts were entered in the software program Atlas-ti. The relevant interview fragments were linked to codes and we tried to find fragments that confirmed or contradicted the quantitative findings. This analysis process was conducted by MDK and step by step discussed with the co-researcher (RP).

Ethics

A study protocol was approved by the Ethics Board of the VU University Medical Center Amsterdam. Before the start of each interview, the interviewee was told that participation was voluntary, that the transcripts would be anonymous and that confidentiality was assured. After that, an informed consent form was signed by the family carer.

Results

Family carer and GP characteristics

The mean age of family carers (n=74) was 62, with a range from 40 to 86. About two thirds of them were female and 41% were employed. The relationship to the patient was that of partner (70%), daughter/son (19%), sibling (4%) or other (7%). The mean age of the GPs (n = 194) was 50, with a range from 31 to 64; 57% were male and 68% had been trained in palliative care. In the qualitative part of the study the mean age of family caregivers (n = 18) was 59, with a range from 44 to 82. Furthermore, 83% were female and the relationship to the patient was that of partner for 72% of them and daughter/son for 22%. Of the18 interviewed family carers six (33%) experienced a fairly heavy to severe burden in the second and third months before death and twelve (66%) one week before death.

Degree of burden

The percentage of family carers who experienced a fairly heavy to severe burden increased significantly from 32% (in the second and third months before death) (CI: 22%-45%) to 66% (one week before death) (CI: 54%-77%) (not in tables). The increasing proportion of carers who felt a fairly heavy or severe burden as the patient came closer to death was often explained in the interviews as due to an accumulation of symptoms and physical deterioration as the patient's death approached; therefore the patient needed more care (table 1, quote 1).

Table 1. Interview fragments of family carers' burden and hospitalisation (Family carers' perspective in interviews, n=18)

	Quotations **I = Interviewer** **F = Family carer**
Degree of burden	**Quote 1** F15 (Woman 47 caring for partner, felt fairly heavy burden in the three time periods) *F: "Well, at first he managed all right - he could make a coffee himself, I mean, and he could take a shower on his own and all that kind of thing. But there comes a point when you see that he needs more and more help and you just feel "I don't know how much longer this is going to go on for but I just want to be there for him for those last few months we've got".*
	Quote 2 F09 (Woman 48 caring for partner, felt no burden in the three time periods): *I: "Didn't you find it hard going?"* *F: "No. I slept on the sofa for a year so well, you just do that, you just do that. (…) But this, well, I don't know, I looked after him and made sure he got what he wanted right up to the end and so, then there's a feeling of satisfaction that I did it properly, that's what you wanted and that makes it all right."*
Type of burden	**Quote 3** F30 (Woman 44 caring for partner, felt severe burden in the three time periods) *I: "You said that it was an emotional burden in the final months?"* *F: "Yes, all the time, yes."* *I: "Can you say more about that? What was the reason?"* *F: "Well, I think it's only logical, you see, you know you're going to lose your husband. But I have to say I was in a daze the whole time, what with the hospital visits, the kids. It seems as if you kind of put your thoughts - your feelings - to one side a bit so that you're there for him and don't make things any worse."*
	Quote 4 F29 (Woman 62 caring for mother, felt some burden in the 2nd and 3th month of patients' life and fairly heavy burden in the last month of patients' life.) *I: "Some people feel an emotional burden at a certain point because they think things are really not going well. Did you have that problem at all?"* *F: "No, I always felt that we should be pleased she had lived as long as she did because she'd always been quite poorly and had things wrong with her heart and so on. So we used to say things like we hadn't expected her to make 90 or 91 with all the problems she'd always had and so on. So it wasn't that I got very emotional about it, I think I'm too down-to-earth for that anyway, you know. We have to be grateful she lived as long as she did."*

Type of burden	**Quote 5** F23 (Man 61 caring for partner, felt severe burden in the three time Periods) *F: “Well, someone who's fully involved in life and doing all kind of things is obviously going to feel incredibly cut off if they lose that ability little by little. (…). She was bothered about those things. And you can’t do anything about it, you can’t… You see, if someone’s hungry you can give them something to eat. If someone’s thirsty you can give them something to drink and if someone’s sad you can put an arm around them. But you can’t do anything about that. You can’t give someone back what they’ve lost.”*
Problem of burden	**Quote 6** F29 (Woman 62 caring for mother, felt some burden in the 2nd and 3th month and life and fairly heavy burden in the last month of patients’ life.) *F: “They [parents] did a lot for me in the past, so that I could carry on working, and now I’d like to repay that. But of course that doesn’t stop it sometimes being a burden.”* **Quote 7** F23 (Man 61 caring for partner: felt severe burden in the three time periods): *F: “Well, I think it’s the confirmation for her, you know, that you are prepared to keep going 24 hours a day for her because you love her, you really love her. But it’s also confirmation for you personally: look, I love that woman so much that this is what I’m prepared to do. And then it’s not about making the effort, that’s not even quite what it is - perhaps it’s difficult to explain. I think it’s significant, it has added value if you have to make an effort.”* *I: “For who?”* *F: “Well, for the relationship I think. I do see it that way.”*
Burden and hospitali-sation	**Quote 8** F25 (Woman 61 caring for a friend, felt no or hardly no burden in the 2nd and 3th month, some burden in the 2nd to 4th week, and fairly heavy burden in the final week of patients’ life) *F: “Yes, the GP thought - saw - that it was getting too much for me as well. Because when he was admitted to (NAME of peripheral hospital), she put so much effort into finding him a place somewhere so that I could get my breath back again.”* *I: “Did that help you, getting your breath back?”* *F: “No, it didn’t. Because not only did I have to go to the hospital every day, that man was also waiting for me there every day. Yes, just like a child waiting for his mum. Kind of “Mummy, I’ve missed you”. Because that man didn’t have anyone else left (cries), I was the only one giving him love and caring for him.”*

Table 1. (continued) Interview fragments of family carers' burden and hospitalisation

Burden and hospitalisation	Quote 9 F09 (Woman 48 caring for partner, felt no burden in the three time periods): *F: "And then one or two weeks in between in hospital and then he'd phone me at 7 in the morning saying can you come and wash me because it takes so long, and they always hurt me, and then I'd spend the entire day in the hospital."* **Quote 10** F04 (Woman 63 caring for partner, felt severe burden in the three time periods): *I: "What did the nurses do?"* *F: "The nurses washed and shaved my husband and had a chat with me over coffee."* *I: "Did the nurses give you support?"* *F: "Yes, they did give me support because they told how everything was going."* *I: "Did you also consider having night-time care?"* *F: "Yes, I tried it for two nights. Because I normally slept on the sofa in the room where he was sleeping. Just when I dropped off to sleep he would get up quietly to go to the toilet but he wasn't able to stand properly. When we had night-time care I slept in my own bed, but I kept waking up. No, it didn't help; I wanted to be with my husband because I didn't know when he would die. I wanted to be with him when he died. It was hard going. But I'd always promised him I would look after him at home."*

The overall degree of burden many family carers mentioned could on the one hand be perceived as severe while on the other hand they found it rewarding to be doing something for their loved one; giving good care was the last contribution they could make (table 1, quote 2). Because of this rewarding feeling, some carers did not describe the burden as fairly heavy or severe in the questionnaire even though they said that they were putting a great deal of effort into caring for their relative.

Type of burden

Of the family carers who felt at least some burden, most experienced emotional burden during the three time periods (85%, 92% and 95%, see table 2). In the interviews, many carers said that knowing the relative was going to die made it an emotionally burdensome period. They felt the loss that was approaching when they looked at their loved one (table 1, quote 3). Some of the carers did not feel a severe emotional burden because their relative had become very old with deteriorating health; in the carer's opinion their time had come to pass away (table 1, quote 4). Also, many family carers mentioned that they felt an emotional burden from watching the patient's suffering. This was not only due to the accumulation of symptoms in the patient, but also due to feeling powerless when seeing the social, mental and physical identity fade away (table 1, quote 5).

Table 2. Degree and type of burden as experienced by family carers during the final three months of life (family carers, n=74*)

	2nd and 3rd months before death	**2nd to 4th weeks before death**	**Final week**
Degree of family carer burden	% (CI 95%)	% (CI 95%)	% (CI 95%)
Not/hardly at all	23 (14-34)	10 (4-19)	8 (3-17)
Somewhat	45 (33-57)	36 (25-48)	26 (16-37)
Fairly heavy	23 (14-34)	33 (22-45)	38 (27-50)
Severe	10 (4-19)	22 (13-33)	28 (19-40)
Type of burden			
(only for family carers with some to severe burden)			
Emotional	85 (72-93)	92 (82-97)	95 (87-99)
Physical	25 (14-38)	27 (17-40)	29 (18-41)

*Between 0-3 missing observations per period.

A significantly smaller proportion of family carers experienced a physical burden in the three time periods (25%, 27% and 29%, see table 2). Care was mostly felt to be a physical burden when the patient was bedbound and needed care in the form of bathing, dressing and toileting. Carers also mentioned the burden of interrupted sleep, communicating with professionals and family, monitoring the patient and being available 24 hours a day.

Problem of burden

Across the three time periods, burden was not perceived to be a problem for 75% of family carers, although one third felt a fairly heavy to severe burden in the second and third months before death and two thirds of them felt a fairly heavy to severe burden in the last month before death (not in table). In the interviews, many family carers said that it was normal to care for and support their partner or parent because previously the loved one had cared a lot for them, and therefore the burden did not feel like a problem (table 1, quotes 6 and 7). This principle of reciprocity was a view held by many family carers but not all of them. The burden was perceived to be a problem when the caring and interrupted sleep continued for a long time without there being a clear idea when it would end.

Association between the characteristics of family caregivers or professional care and the degree of family caregiver burden

For family carers' age, gender, relation to the patient, employment of family carers, number of family caregivers, number of GP visits and received nursing care no significant association was found between family carers with a high level of burden and a low level of burden during the second to fourth weeks before the patient's death (table 3). For the other two time periods, one week before death and second and third months before death we found no significant associations (not in table).

Table 3. Association between the characteristics of family caregivers or (professional) care and the degree of family caregiver burden in the 2nd to 4th week before death. (n = 74)*

	Fairly heavy to severe burden (n = 40)	**No to some burden (n = 31)**	
	%	**%**	***P* value**
Family caregiver characteristics			
Main family carer			
Age (mean, SD)	63 (SD 13)	62 (SD 11)	0.50
Gender, male	27	32	0.66
Partner of patient	70	68	0.83
Employed	43	43	0.94
Number of other caregivers			0.18
No other family carers	11	30	
1-2 other family carers	53	33	
3-5 other family carers	21	23	
> 5 other family carers	16	13	
Characteristics of care			
GP visits			0.60
No visits	5	4	
1 visit	34	46	
2 or more visits	61	50	
Nursing care	85	69	0.12

*Three missing observations.

GPs’ assessment of family carers’ burden

GPs were more likely to assess family carers as having a fairly heavy or severe burden than the family carers’ self-assessment (Figure 1). In the three periods, the assessment of the burden by GPs agreed with that by family carers in 32%, 35% and 30% of cases respectively (table 4). A large proportion of GPs estimated family carers’ burden to be higher during the three periods (35%, 41% and 47%); the opposite of this, a lower estimation of family carers’ burden, was found for 30%, 24% and 24% of the dyads respectively. The level of agreement was poor at two to three months before death (Kappa = 0.19) and poor at two to four weeks before death (Kappa = 0.13). No weighted Kappa coefficient could be calculated for the final week because observed concordance was smaller than mean-chance concordance.

Fig 1. Proportion of family carers and GPs who perceived family carers’ burden to be fairly heavy or severe in the final three months of the patient’s life (Dyads of family carer and GP perspectives (n=65)

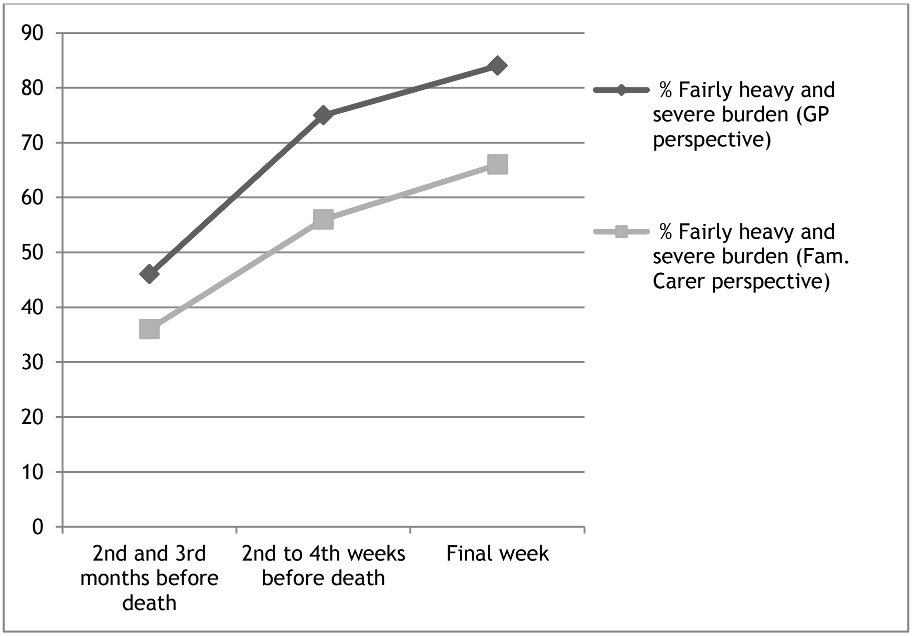

Table 4. Assessment of family carer burden and level of agreement (Dyads of family carer and GP perspectives, n = 65*)

		Family carer perspective				
		Not/hardly at all	Somewhat	Fairly heavy	Severe	Total
Second and third months before death						
GP perspective	Not/hardly at all	3 (4.8%)	7 (11,3%)	1 (1.6%)	0	11 (17.7%)
	Somewhat	6 (9.7%)	9 (14.5%)	7 (11.3%)	0	22 (35.5%)
	Fairly heavy	2 (3.2%)	11 (17.7%)	7 (11.3%)	5 (8.1%)	25 (40.3%)
	Severe	0	2 (3.2%)	1 (1.6%)	1 (1.6%)	4 (6.5%)
		11 (17.7%)	29 (46.8%)	16 (25.8%)	6 (9.7%)	62 (100%)
		Kappa with linear weighting 0.19 (CI 95% 0.02-0.35)				
Second to fourth week before death						
GP perspective	Not/hardly at all	0	0	1 (1.6%)	0 0	1 (1.6)
	Somewhat	1 (1.6%)	6 (9.5%)	5 (7.9%)	2 (3.2%)	14 (22.2%)
	Fairly heavy	4 (6.3%)	14 (22.2%)	9 (14.3%)	7 (11.1%)	34 (54%)
	Severe	0	3 (4.8%)	4 (6.3%)	7 (11.1%)	14 (22.5%)
		5 (7.9%)	23 (36.5%)	19 (30.2%)	16 (25.4%)	63 (100%)
		Kappa with linear weighting 0.13 (CI 95% 0–0.29)				
Final week						
GP perspective	Not/hardly at all	0	0	2 (3.1%)	0	2 (3.1%)
	Somewhat	3 (4.7%)	1 (1.6%)	3 (4.7%)	1 (1.6%)	8 (12.5%)
	Fairly heavy	1 (1.6%)	9 (14.1%)	7 (10.9%)	9 (14.1%)	26 (40.6%)
	Severe	1 (1.6%)	7 (10.9%)	9 (14.1%)	11 (17.2%)	28 (43.8%)
		5 (7.8%)	17 (26.6%)	21 (32.8%)	21 (32.8%)	64 (100%)
		A linear Kappa cannot be calculated because observed concordance is smaller than mean-chance concordance				

*Between 1–3 missing observations per period.

Association between GPs' assessment of family carers' burden and hospitalisation in final week of life

In a multivariate analysis of patients who spent most of the time at home, after correcting for age and living alone, no significant association was found between the GPs' assessment of the degree of family carers' burden during the second to fourth weeks before the patient's death, and patient hospitalisation in the final week (table 5).

Table 5. Association between GPs' assessment of family carers' burden during second to fourth week before patients' death and hospitalisation in the final week (GP perspective, n = 194)

	Total (n = 194)	**No hospitalisation in final week (n = 161)**	**Hospitalisation in final week (n = 33)**		
	%	%	%	Odds (CI 95%)	
No to some burden	31	30	36	1	
Fairly heavy burden	46	45	49	0.76	(0.32-1.78)
Severe burden	23	24	15	0.42	(0.13-1.34)

*Multivariate analysis after correction for age and living alone.

In the interviews, some family carers said that the burden was one of the reasons for hospitalisation. Although the physical burden was reduced for many family carers due to the patient receiving 24-hour professional care in the hospital, sometimes they continued to care for the patient. In addition, hospitalisation could also give rise to other burdens, for example feeling responsible for checking the professional care such as the provision of medication or dealing with inattentive professionals (table 1, quotes 8, 9). The shift from one type of burden to another type was also mentioned when more care was arranged at home. Other family carers, community nurses and night-time care could often relieve the family carers' physical burden. But sometimes this help was perceived more as an extra emotional burden than as relief (table 1, quote 10).

Discussion

In this study we looked at the unique combination of family carers' and GPs' perspectives on family carers' degree, type and change of burden in the last three months of the patient's life and whether this is associated with hospitalisation. The proportion of family carers experiencing a fairly heavy to severe burden increased from one third during the second and third months before death to two thirds in the final week. Most carers felt an emotional burden and a smaller proportion experienced a physical burden. Three-quarters of carers did not perceive their burden as a problem. The interviews showed that this was explained by the fact that caring for and supporting their relative often felt rewarding and it was the final thing they could do for their loved one. No significant association was found between the characteristics of family caregivers or professional care and the degree of family caregiver burden. Also there was no significant evidence that patients of family carers of whom the GP assessed a fairly heavy to severe burden, were more likely to be hospitalised.

Strengths and weaknesses

A strength of this study is the new insights provided in how the burden for family carers changes as patients come closer to death, from the perspective of both carers and GPs, and the association with hospitalisation. The generalisability of the findings may be limited because of the low response rate of GPs and carers. The reason for the low GP response rate may be the complex procedure of asking the GPs to invite carers to participate in the research. However there is little difference between the mean age and gender breakdown in our GP sample and the general population of Dutch GPs, for whom the mean age is 48 and where 59% are male [26]. Half of the GPs did not invite the carers to participate in the study; 31% of these GPs did not do so because they thought it would be too burdensome for the carers. Because of this, there may be an underestimation of the family carer burden. A further limitation is the retrospective design of the study. In assessing the burden of family carers, recall bias cannot be excluded from both the family carer him/herself as from the GP. However, because both GPs and carers filled in the questionnaire retrospectively, we don't know in which direction this might have affected the outcome. Our results should be interpreted with caution because no validated questionnaire is used. However, our one item question about degree of burden is comparable with the one item overall question about burden in the 'Zarit Burden Interview' which was tested as a useful screening instrument.[7]

Family carers' burden and support

Many family carers perceived the burden not to be a problem. Many carers said in the interviews that caring felt rewarding and important to do because it was the final thing they could do for their loved one. These positive feelings of reward and the perceived value of the care they provide help carers to cope with the situation were confirmed in in-depth studies with a cross sectional design.[4,8,27]

The importance of coping with the situation may explain why many carers did not feel their burden to be heavy even when they spent a great deal of effort on caring for their relative in objective terms. In addition to this, our research shows that although a proportion of 66% family carers experienced a fairly heavy to severe burden in the last week of life, only a proportion of 25% perceive burden as a problem. Therefore it is recommended to GPs not only asking about the degree of burden, but also to ask whether the burden is perceived as a problem for the family caregiver.

GP’s assessment of family carer’s burden

An important result of this study is that GPs tended to assess the burden to be higher than family carers did in their self-assessment. In more than one third of the cases, the GPs estimated the burden to be higher, although in more than one fifth of the cases they estimated the burden to be lower. Given the above-mentioned results that carers do not always perceive their burden to be as high as one would expect on the basis of care activities, it is debatable whether these higher GP estimations are an overestimate rather than the lower family carer assessment being an underestimate. Overestimation by GPs might be a problem if GPs’ assessment of family burden is a reason for hospitalisation. However, in this study no evidence was found that the likelihood of hospitalisation was higher for patients for whom the GP had assessed fairly heavy or severe family caregiver burden. However, in some interviews it was explained that hospitalisation was chosen as a solution to give respite to the carers, especially for those who had cared for a long time. But then other kinds of burden could arise.

Conclusion

In order to understand the overall degree and development of burden and needs of family carers, it is important for GPs to discuss the multi-dimensionality of burden and the felt problem of burden regularly with carers, so that they can anticipate family carers’ personal needs. More research is needed to know when, and for whom, the burden becomes excessive for family carers at the end of life.

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Part 2

Avoidability of hospitalisations at the end of life

Chapter 5

General practitioners' perspectives on the avoidability of hospitalisations at the end of life; A mixed-method study

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Abstract

Background

Many patients are hospitalised in the last months of life. Little is known about the avoidability of these hospitalisations.

Aim

To explore whether and how hospitalisations could have been avoided in the last three months of life and barriers to avoid this, according to general practitioners (GPs) in the Netherlands.

Methods

Sequential mixed method design, starting with a cross-sectional nationwide questionnaire study among GPs, followed by in-depth interviews. GPs were asked about their most recent patient who died non-suddenly and who was hospitalised in the last three months of life. Additionally, 18 of these GPs were interviewed in depth about the situation surrounding hospitalisation.

Results

According to 24% of 319 GPs, the last hospitalisation in the final three months of their patient's life could have been avoided. Of all avoidable hospitalisations, 46% could have been avoided by proactive communication with the patient, 36% by more communication between professionals around hospitalisation, 28% by additional care and treatment at home, and 10% by patient and family support. In the in-depth interviews, GPs confirmed the aforementioned strategies, but also mentioned various barriers in daily practice, such as the timing of proactive communication with the patient, incompleteness of information transfer in acute situations and the lack of awareness among patients and family that death was near.

Conclusion

A proactive approach could avoid some of the hospitalisations at the end of life, in the opinion of GPs. More insight is needed in communication and psychological barriers for timely discussions about end-of-life issues.

Introduction

Many patients are hospitalised during the final phase of life.[1,2] The proportion of patients who are transferred from home to hospital in the last three months of life is 55% in the Netherlands and 60% in Belgium. In Canada, 68% are transferred to hospital in the last six months of life.[1-3] Staying at home is not only preferable from the perspective of the majority of patients[4-7] but also from the perspective of healthcare costs.[8] In addition, a high proportion of hospitalisations in the population as a whole is considered to be an indicator of poor quality in end of life care.[9] While staying at home at the end of life is preferred, little is known about the avoidability of hospitalisations.

The reasons most commonly given for the hospitalisation of patients at the end of life are falls/confusion or deterioration, cancer complications, and COPD exacerbation.[10] For Canadian lung cancer patients, dyspnea, pain, an inability to cope at home, and altered level of consciousness are the most important reasons for hospitalisation.[11]

In a large study in the US based on experts assessing diagnostic codes in patient records, it was found that 26% of the hospitalisations of patients receiving home-based and community-based services could potentially have been avoided.[12] A British study based on chart analyses suggested that 33% of hospitalised patients who were identified as being in the last year of their life could have been treated at home.[13] A lower proportion of 7% potentially avoidable hospitalisations was identified in another British chart study of hospitalised palliative care patients, with most of these patients being referred because of confusion, general deterioration or symptom control.[10]

These studies about avoidable hospitalisations are based on chart reviews and assessment by clinical experts. To unravel the avoidability of hospitalisations, it is also important to know the opinion of GPs about whether and how hospitalisations of their patients at the end of life could have been avoided.

More insight into which hospitalisations could have been avoided and in what way is important for GPs and other caregivers in letting them enable patients to remain at home at the end of life.

Therefore the aims of this study are; to explore for how many patients hospitalisation could have been avoided, according to GPs; how hospitalisation could have been avoided, barriers in avoiding hospitalisations and to explore the characteristics of avoidable versus unavoidable hospitalisations in the final three months of patients' lives.

Method

Design

A mixed-method study was conducted using a sequential strategy.[14] Firstly, we conducted a nationwide retrospective cross-sectional questionnaire study among Dutch GPs in 2011 (table 1.). In the questionnaire, GPs were asked to recall their most recently deceased adult patient who died non-suddenly and who was hospitalised in the final three months of life. When this patient underwent multiple hospitalisations, we asked for the last hospitalisation before death and hospitalisation was defined as admission to a hospital for at least one night. Secondly, in-depth qualitative interviews were conducted with a selection of the GPs to explore in depth how hospitalisation could have been avoided and the barriers for this (table 1).[15] In the Netherlands, GPs are responsible for palliative care patients living at home and mostly have long term relationships with patients and their families."

Table 1. Overview of research aims and the method(s) used to study them

Research aims	Quantitative questionnaire study	Qualitative in-depth interview study
1. Explore for how many patients hospitalisation could have been avoided, according to GPs.	Yes (Closed question)	No
2. How hospitalisation could have been avoided, according to GPs.	Yes (Closed question, table 4)	Yes (Open question)
3. Barriers in avoiding hospitalisations.	No	Yes (Open question)
4. Explore the characteristics of avoidable versus unavoidable hospitalisations in the final three months of patients' lives.	Yes (Open en closed questions, table 2)	Yes (Open question)

Study population

Quantitative questionnaire study. A random sample of 1200 GPs was selected from 8896 registered GPs in the Dutch “Medical Address book” of 2010. Respondents had to be working as a GP at the time of the data collection. Of the 1200 GPs in the sample, 150 were not working as a GP when the questionnaire was sent and 100 did not have patients who met the criteria. This resulted in 950 eligible GPs, of whom 322 filled out the questionnaire (34%). Three GPs were excluded because they had not filled out the core question about the avoidability of the hospitalisation, leaving 319 questionnaires to be analyzed.

Qualitative in-depth interview study. In the questionnaire, GPs were asked whether they would be willing to participate in the in-depth interview study as well. Of the GPs responding positively to this request, 18 were selected purposively. The purposive sample was based on diversity in GPs’ age, degree of urbanization, patients’ age and patients’ disease.

Measurements

Quantitative questionnaire study. The written questionnaires were developed using relevant literature[1,2,13] and in-depth interviews with five physicians. A draft of the questionnaire was tested among 14 GPs. Their comments were incorporated in the final version of the questionnaires. The questionnaire included one open question about the most important reason for the last hospitalisation and closed questions about the characteristics of the last hospitalisation, such as who initiated the hospitalisation, whether an acute episode and/or a diagnostic goal played a role in hospitalisation, and the patient’s prognosis just before death. Finally, GPs were asked whether in retrospect they thought that hospitalisation for this patient could have been avoided and to indicate how hospitalisation could have been avoided by selecting from pre-structured options.

Qualitative in-depth interview study. Of the 18 in-depth interviews, 16 were held face-to-face at the GP’s surgery and two were held by telephone. The mean interview time was on average one hour. The interviews started with a ‘grand tour’ question: “Tell me about the situation of the patient for whom you filled in the questionnaire around the time of the hospitalisation”. After exploring the patients’ circumstances around the time of the hospitalisation, questions were asked about the avoidability of the hospitalisation. Interviewees were also asked about other recent cases where the GP thought that hospitalisation could have been avoided and, in contrast, about patients who were not hospitalised in the last three months of life. These in-depth interviews were conducted by a nurse experienced in interviewing (MDK) in the first half of 2012.

Analyses

Quantitative questionnaire study. Analyses were performed for hospitalisations that could have been avoided and hospitalisations that could not have been avoided according to the GP. A Chi-square test or Fisher's exact test (for low numbers) was used to assess the significance of differences between avoidable and unavoidable hospitalisations.

Qualitative in-depth interview study. The interviews were transcribed verbatim and examined thoroughly. The first transcripts were read thoroughly and the first codings were discussed by two researchers experienced in qualitative research (MDK and HRP).Then a coding scheme was conceived in a deductive manner,[16] using the main answers given in the questionnaire study on how hospitalisations could have been avoided. The coding scheme and interview transcripts were entered in the software program Atlas-ti. The relevant interview fragments were linked to the codes. In the analysis we tried to find fragments that confirmed, contradicted, and/or refined the quantitative findings. This qualitative analysis process was discussed step by step by the first author and the co-researcher (HRP). Peer debriefing was conducted by all authors; BS has 40 years' experience as a general practitioner and in palliative care and AF, BO and LD have more than 15 years' experience in qualitative and palliative care research.

Results

Demographic characteristics of the participants

The mean age of the 319 GPs who filled out the questionnaire was 49, with a range from 31 to 64 years; 55% were male, 6% had completed specialised training in palliative care, and 46% worked in a highly urbanised environment. The mean age of the 18 GPs interviewed was 50, with a range from 32 to 64 years; 14 (78%) were male, one (6%) had undertaken specialised training in palliative care, and 7 (39%) worked in a highly urban environment (not in table).

Demographic and clinical characteristics of hospitalised patients (table 2)

The last hospitalisation in the final three months of their patient's life could have been avoided according to 77 (24%) of the 319 GPs. In total, 31% of all hospitalised patients were aged over 80, 57% were male, 65% had died of cancer, 51% had multimorbidity and 32% died in hospital. No significant differences were found in patients' demographic and clinical characteristics between avoidable and unavoidable hospitalisations.

Table 2. Demographic and clinical characteristics of patients with avoidable hospitalisations compared to unavoidable hospitalisations, according to the GP

	All hospitalisations (n=319) %	Avoidable (n=77) %	Unavoidable (n=242) %	*P* value
Age				
<65	30	31	30	0.917
65-79	39	37	40	
>80	31	32	31	
Gender				
Male	57	59	56	0.624
Cause of death				
Cancer	65	60	66	0.374
Cardiovascular disease	15	20	14	0.231
Respiratory disease	11	11	11	0.947
Stroke (CVA)	2	0	3	0.203
Other diseases	7	9	6	0.367
Multimorbidity				
2 diseases	28	24	29	0.338
3 or more diseases	23	30	20	0.069
In-home family caregivers	66	68	65	0.768
Place of death				
Home	50	54	48	0.270
Hospital	32	25	34	
Home for the elderly	5	7	5	
Nursing home	3	1	3	
Inpatient hospice	10	12	10	

Characteristics of and reasons for hospitalisation (table 3)

The most common reasons for hospitalisation were respiratory symptoms (31%), digestive symptoms (17%), and cardiovascular symptoms (14%). An acute episode (73%) and a diagnostic goal (44%) often played a role in hospitalisation. A proportion of 41% of the patients had a prognosis of a few weeks or less, 41% of the patients stayed in the hospital for more than 7 days, and the hospitalisation was initiated most often by the patient's own GP (46%). The following significant differences ($p<0.05$) were found in avoidable hospitalisations in comparison with non-avoidable hospitalisations, as assessed by the GPs: in avoidable hospitalisations social circumstances were more often the most important reason for hospitalisation (6% versus 2%), an acute episode played a role less often before hospitalisation (62% versus 76%), a diagnostic goal played a role less often (26% versus 49%), and there was a life expectancy of a few weeks or less more often (52% versus 37%). In cases where the GP had initiated the hospitalisation (n=146), significantly ($p<0.05$) more GPs who assessed the hospitalisation as avoidable considered not hospitalising the patient (62% versus 25%) and discussed this option with the patient (76% versus 54%) compared to the GPs who assessed the hospitalisation as unavoidable.

Table 3. Characteristics of avoidable hospitalisations compared to unavoidable hospitalisations, according to the GP

	All hospitalisations (n=319)	Avoidable (n=77)	Unavoidable (n=242)	
Characteristics of the last hospitalisation	%	%	%	*P* value
Most important reasons for hospitalisation*				
Symptomatic reasons	85	84	85	0.901
Respiratory	31	30	31	0.820
Digestive	17	13	18	0.278
Cardiovascular	14	14	14	1
Pain	6	5	6	0.734
Psychological	4	6	3	0.224
Fracture	4	3	4	0.530
Other symptomatic reasons	16	17	16	0.896
Social reasons	4	8	2	**0.028**
Diagnostic reasons	5	1	7	0.083
Treatment	10	13	8	0.225
Aspects that played a role in hospitalisation				
Acute situation	73	62	76	**0.015**
Diagnostic goal	44	26	49	**<0.001**
Prognosis before hospitalisation				
A few weeks or less	41	52	37	**0.019**
Length of hospitalisation				0.540
1-2 days	27	29	27	
3-6 days	32	34	31	
1-2 weeks	27	22	28	
3-4 weeks	11	14	10	
> 4 weeks	1	0	1	
Person who initiated hospitalisation				
Patient's own GP	46	38	49	0.113
GP locum	28	34	27	0.197
Patient and/or family	10	12	10	0.718
Medical specialist	13	15	13	0.562
Other	2	1	3	1
Only for GPs who initiated hospitalisation:	% (n=146)	% (n=29)	% (n=117)	
GP had considered not hospitalising patient	33	62	25	**<0.001**
Just before hospitalisation, the GP discussed the option of not hospitalising with the patient and/or family	59	76	54	**0.036**

*More than one answer could be given

Table 4. How hospitalisation could have been avoided, according to the GP*

	Avoidable hospitalisations (n=77)		All hospitalisations (n=319)
	n	%	%
Proactive communication with the patient	**35**	**46**	**11**
Early discussion about withholding treatment in hospital	23	30	7
Early discussion about limited prognosis	17	22	5
Early discussion about withholding diagnostics in hospital	10	13	3
Medical specialist informed the patient that illness was incurable	10	13	3
Other proactive communication with the patient	3	4	1
Communication between professionals relating to hospitalisation	**28**	**36**	**9**
Medical specialist consulted GP before hospitalisation	13	17	4
Clear information transfer to the out-of-hours general practice	10	13	3
Nurses informed GP early about symptoms	5	7	2
Consultation of a specialized palliative care consultation team	4	5	1
Other communication between professionals	6	8	2
Additional care and treatment outside the hospital	**22**	**28**	**7**
Early start of nursing care	11	14	3
Transfer to inpatient hospice	11	14	3
Initiation of night-care services	6	8	2
Treatment at home	3	4	1
Initiation of care by volunteers	1	1	0
Other caregiving	1	1	0
Patient and family support	**8**	**10**	**3**
More support to informal care givers	4	5	1
Instruction to patient and/or family about symptoms	3	4	1
Provide and give instructions about “if needed” medication	3	4	1
Other patient and family support	3	4	1
Other strategies	8	10	3

*More than one answer could be given

Strategies to avoid hospitalisations (table 4)
Of the 77 hospitalisations that were retrospectively perceived as avoidable, 25% of the GPs reported two strategies and 27% reported three or more strategies that could have helped avoid the hospitalisation (not in table). Of all the avoidable hospitalisations, 46% could have been avoided by proactive communication with the patient, including talking about withholding treatment and diagnostics, 36% by more communication between professionals around hospitalisation, 28% by additional care and treatment at home, and 10% by patient and family support.

Similar strategies to the ones mentioned in table 4 emerged from the in-depth interviews. However, the interviews revealed complexities in practice that could form barriers to applying these strategies. This will be elaborated on below.

Proactive communication with the patient
GPs talked in the in-depth interviews about the importance of proactive communication about withholding treatment in the hospital. Opportunities to start this communication could arise, for example, when a patient took the initiative to discuss an advanced directive with the GP (e.g. for euthanasia or a do-not-resuscitate order) or after a medical specialist had phoned the GP to inform that there were no more curative treatment options. Although many GPs stressed the importance of proactive communication, GPs explained that proactive communication often did not take place because the GPs found it difficult to find the right moment to talk about this. Finding the right moment was difficult in the case of patients who had an unexpectedly fast deterioration process from a progressive cancer, for patients who seemed still very active and not very ill at first glance, or also for patients in a slow deterioration process, as is often the case for the very old patients.

GP26: About a man (aged 96) with Alzheimer's disease; there was a slight deterioration, he was living at home with a 62-year-old woman and had an acute CVA.
Interviewer: What was the reason why the possibility of talking about the impending death was never raised?
GP: I think basically that this wasn't yet really relevant while he was still reasonably okay and it was still possible to hold a conversation with him, and when he basically started deteriorating and getting dementia it wasn't really technically possible to have that conversation. So I really felt, well, now there was not much point any more in talking about this with that man because would he even understand what I was talking about? Well, perhaps there's a gray area in between where you can say: perhaps we could still have done that, but that requires you as the GP to actively work out that man is so

old now and he's getting a bit worse, shouldn't I pay him a visit now to talk to him. Well, you don't normally manage that in day-to-day practice.

Communication between professionals around hospitalisation

GPs said in the interviews that an important condition for avoiding hospitalisations was continuity of care to be guaranteed in the out of hours. Several of the GPs interviewed also gave their mobile number towards the end of the patient's life, and wrote down the patient's preferences in the digital record that was available for the locum GPs working in the out-of- hours practice. However, sometimes the GP had not yet taken such anticipatory measures in the case of diseases that were progressing fast. GPs also indicated that even when they had taken such measures in anticipation, locums did not always read the complete digital record, especially in the case of heart failure or cerebral vascular accidents, because then it is assumed that "every minute counts". If there was little information in the digital records for the locum about a patient's limited life expectancy and the patient's preferences, the locum often felt that the best choice was to refer the patient to a hospital.

GP29: You do get situations where they phone up in panic saying oh, my father's got pains in his chest and the ambulance arrives to pick them up - whereas they're basically dying of prostate cancer. Which makes me think, hold on a minute guys. That pain in the chest comes from the bone metastases, now that's not a job for the cardiologist at all, that can sometimes be one of the best ways to die. (…) That assessment has to be made by a doctor, in the person's home, in short order. (…) In principle you can see just the same information at the out-of-hours general practice here. In fact, we have a laptop here that you can take with you to the home that lets you view the entire file.
Interviewer: Does that file show sufficiently clearly that someone has a limited life expectancy?
GP: Not always, but that's an extra task for the person's own general practitioner to record that clearly somehow or other, and we still need to make agreements to arrange that. (…) Otherwise, if you don't have a file, it gets difficult for the out-of-hours general practice that doesn't have any information. Yes, then perhaps you should go for the safe option and just send in all the people like that. But if you do have access to that information, then I feel you should, well, use that information for an individual assessment. (…) Don't automatically pull out all the stops. Look, 'every minute counts' applies if you want to save something and that's the case for the heart, if you want to save the heart muscle tissue with an acute stent, in order to make sure these people stay in the best possible condition, but that's not so important for everyone.

Additional care and treatment outside the hospital

GPs said that nurses were often important in enabling family carers to continue care at home. Without the support, care and observation of a nurse, it would be too burdensome for the family carer. Some GPs started early in arranging nursing care at home for the patient and family, and asked a nurse to make weekly visits to discuss the patient's care needs with them and their family and also to get the patient used to nursing care. However, GPs said that some family carers wanted to do everything themselves. In cases in which there was no family carer living in the patients' home, day and/or night nursing care could have helped avoid hospitalisation, but was not accepted by the patient.

GP22: About a patient with colon carcinoma who wanted to go to het hospital
Well, this couple - how do I put this diplomatically? - they were a couple of cards short of a full deck. So it was very difficult to explain things, they had some kind of aversion to home care and I've never been able to find out what that was about. His wife died eighteen months later from ovarian cancer. Though that did go well; we kept her at home. With home care too, and she said at one point, well, that's a shame, we could have done that with my husband too.

Patient and family support

Several of the GPs interviewed said that they had informed the patients and family about acute symptoms or situations they could expect, such as pain or dyspnea, and told them they could always call the GP if something happened. But if there was an acute episode, there was panic at the patient's home and then sometimes a medical specialist in the hospital would be called, resulting in a hospitalisation.

GP12: About a lung cancer patient, male 67 years. The GP had explained to the patient and his wife what could happen in case of dyspnea. After a hospitalisation for hemoptysis, the patient had said that he would not go to the hospital anymore.
Because they said "I won't go back to the hospital the next time". But then he starts coughing up blood again and they go after all; apparently they start to panic, they get some kind of panic reaction. Then they call up the specialist directly, saying "I'm coughing up blood, what should I do?" "Well," says the specialist, "come along" - and then he admits him again. Then I think, okay, what did you have to do that for?

GPs also said that they were often confronted with patients and family who were not ready to accept that the end was near. The most difficult situation for GPs was to support family who were not aware of the patient's deterioration or family who almost never visited the patient and still "demanded" an intervention by the GP, which often resulted in an acute hospitalisation.

Discussion

Main findings and comparison with other studies

This study shows that 24% of the hospitalisations in the final three months of GPs' patients who died non-suddenly could have been avoided, according to the GPs. Proactive communication with the patient, communication between professionals around hospitalisation, arranging additional care and treatment at home, and patient and family support were the strategies most often mentioned to avoid hospitalisation. The in-depth interviews with GPs confirmed these strategies, but also revealed various barriers in daily practice, such as difficulties in the timing of proactive communication with the patient, the incompleteness of information transfer in acute situations, and the lack of awareness of patients and family that death is near.

We found that a quarter of hospitalisations could have been avoided based on the retrospective perspective of the GP treating the patient. Other studies showed that 7%[10], 24%[12], and 33%[13] of hospitalisations of patients with a short life expectancy could have been avoided; these estimates were based on clinical experts' opinions reviewing hospital charts. Valid comparisons of these results are hampered due to different perspectives, different populations, and different strategies for assessing whether hospitalisations were avoidable.[10-13] Nevertheless, these previous studies also suggest that hospitalisations at the end of life can be reduced in order to help patients remain at home up to the end of life.

For practice it is relevant that our study shows that a proactive approach, in various forms, is the most common suggestion given by GPs on how they could have avoided the hospitalisation in retrospect. Other studies have confirmed that proactivity can indeed help avoiding hospitalisations, for instance, studies that included proactive monitoring and timely discussion with the patient/family about their preferences and what might happen at the end of life.[17,18] Furthermore, information transfer from the GP to the out-of-hours general practice[19] or the availability of appropriate "as needed" medication[20] were proactive approaches shown to be capable of reducing hospitalisations. The answer to why the GPs in our study did not act sufficiently proactive to avoid the hospitalisation can be found in the in-depth interviews with the GPs. There, the GPs mentioned various barriers to a proactive approach. One of the barriers mentioned is the difficulty of finding the right time for proactive communication with the patient. The difficulty in recognizing that patients are in need of palliative care is confirmed by other studies[21,22] Clinical indicators are available for the timely recognition of palliative care needs, such as the Gold Standards Framework.[23,24] However, these clinical indicators do not eliminate other communicative and psychological barriers, mentioned by the GPs, that may hinder timely end-of-life discussions. One of the communicative and psychological barriers, namely both physician and patient hidden awareness that the patient is dying, has already been described extensively in the classic study by Glaser and Strauss.[25,26] These clinical, communicative, and psychological aspects underline the complexity of a proactive approach to end-of-life care. Given this complexity, it can be questioned whether in daily practice GPs really will be able to act proactive in all potentially avoidable hospitalisations (25%). Furthermore, other aspects also influence hospitalisation, such as the patient preference for hospitalisation or an acute episode which makes the hospitalisation unavoidable. In these cases a hospitalisation can be the most preferable option.

Previous studies of avoidability of hospitalisations based their assessment mainly on clinical aspects, such as diagnosis, comorbidity, and the reason for admission.[12,13] Our study did not find significant differences between avoidable and unavoidable hospitalisations for these clinical aspects. However, significant differences were found for life expectancy, social reasons, and for patients for whom an acute episode and/or a diagnostic goal played a role in the decision for hospitalisation. Although for 44% of patients a diagnostic goal played a role in the decision for hospitalisation, this was the most important reason for hospitalisation for a low proportion of patients (5%). These aspects were not mentioned in other research into avoidable hospitalisations at the end of life and they add new insights into the complexity surrounding hospitalisation at the end of life.

Strengths and limitations of the study

The strengths of the nationwide study presented here are the new insights about how hospitalisations could have been avoided from the GPs' perspective and the mixed method design in which we have combined a quantitative questionnaire study with information from in-depth interviews with GPs. A limitation is the weakness of evidence that the suggested strategies could have avoided hospitalisations at the end of life. In order to find stronger evidence, it is recommended to test these strategies in a stronger research design, such as a clinical trial. However, the strategies the GPs mentioned are found in other studies to help avoiding hospitalisation (as described in the discussion). Above that, also other aspects influence hospitalisation, such as the patient preference for hospitalisation or an acute situation which makes the hospitalisation unavoidable. In these cases a hospitalisation can be the most preferable option. Another limitation is the low response rate in the quantitative part of the study. However, since the characteristics of the respondents in our study sample do not differ from the general Dutch population of GPs[27], we presume this has a limited effect at most on the validity and generalizability. Another limitation is the potential recall bias of GPs in this retrospective design. Therefore in the in-depth interviews we asked also about more recent cases.

Conclusion

This study provides insights into the differences between avoidable and unavoidable hospitalisations at the end of life and strategies for avoiding hospitalisations from a GP perspective. According to GPs, a quarter of all hospitalisations could have been avoided and nearly half of the avoidable hospitalisations could have been avoided by proactive communication. For practice it is recommended to provide more attention to proactive communication and the communicative and psychological barriers to timely communication between GPs, patients, and family carers about limited prognoses, withholding treatment, and diagnostics at the end of life.

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Chapter 6

How could hospitalisations at the end of life have been avoided? A qualitative retrospective study of the perspectives of general practitioners, nurses and family carers

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Abstract

Background

Although many patients prefer to stay and die at home at the end of life, many are hospitalised. Little is known about how to avoid hospitalisations for patients living at home.

Aim

To describe how hospitalisation at the end of life can be avoided, from the perspective of the GPs, nurses and family carers.

Method

A qualitative design with face-to-face interviews was used. Taking 30 cases of patients who died non-suddenly, 26 GPs, 15 nurses and 18 family carers were interviewed in depth. Of the 30 patients, 20 were hospitalised and 10 were not hospitalised in the last three months of life.

Results

Five key strategies that could help avoid hospitalisation at the end of life emerged from the interviews. The key strategies were: 1) marking the approach of death, and shifting the mindset; 2) being able to provide acute treatment and care at home; 3) anticipatory discussions and interventions to deal with expected severe problems; 4) guiding and monitoring the patient and family in a holistic way through the illness trajectory; 5) continuity of treatment and care at home. If these five key strategies are followed in an interrelated way, this could help avoid hospitalisations, according to GPs, nurses and family carers.

Conclusion The five key strategies described in this study can help avoid hospitalisation at the end of life. It is recommended that for all patients residing at home, GPs and community nurses work together as a team from the moment that it is marked that death is approaching up to the end of life.

Introduction

Hospitalisations at the end of life are a concern for many patients, because most of them prefer to stay at home and to be cared for there.[1-3] For instance, in the Netherlands and Belgium, more than half of the patients residing at home are hospitalised in the last three months of life and most of these hospitalised patients die in hospital.[4;5] A high proportion of hospitalisations at the end of life in the population is considered a problem because of the high healthcare expenditure [6] and because it is an indicator of poor quality in end-of-life care.[7] In general, the reasons most commonly given for the hospitalisation of patients at the end of life are somatic symptoms (such as dyspnoea, digestive, cardiovascular problems and pain), psychological problems (such as confusion or altered level of consciousness), or social problems (such as inability to cope at home).[8-10] However, it has been suggested that these problems can often be managed at home.[11]

For hospitalised patients with a short life expectancy, it has been estimated that 7% to 33% of hospitalisations could have been avoided, according to clinical experts' assessments using hospital charts and professionals working in the hospital. [8;11;12] A focus group study among (clinical) professionals found that the main reasons for inappropriate hospitalisations were family carers being unable to cope at home, the 'rescue culture' of modern medicine, the costs of receiving community services and the availability of community services, and practice within the homes for elderly.[13]

We acknowledge that hospitalisation at the end of life can be unavoidable or actually desirable for some patients, for instance when patients consider the hospital as a 'safe haven' or in very complex situations at home.[13;14] However, because of the patients' preferences and the quality of care, and also from an economic perspective, it is important to know more about the avoidability of hospitalisations from home. Only one focus group study has described the reasons for inappropriate hospitalisations.[13] To unravel the avoidability of hospitalisations from home, it is important to know what the situation was at home for the patients who were hospitalised and those who were not hospitalised, and how to avoid hospitalisation from the perspective of professionals providing care in the patient's home and family carers. Therefore, this study aimed to describe how hospitalisation at the end of life can be avoided, from the perspective of GPs, community nurses and family carers.

Methods

Design

A qualitative descriptive study was conducted focusing on cases of deceased patients who resided at home, some of who were hospitalised and others who were not hospitalised at the end of life. Retrospective qualitative in-depth interview study was performed and analysed, using an inductive thematic approach [15], in the first half of 2012.

Study population

This qualitative study is an addition to a broader national questionnaire study among GPs in the first half of 2011.[16] In this questionnaire study, GPs were asked about the last deceased patient who died non-suddenly. The GPs were asked to send a letter to the most important family carer to ask if he/she was willing to participate in the study. Also in the questionnaire was already asked for the nurse, if involved, and then the most involved nurse was asked to participate in the study. For this qualitative study we purposively selected 20 hospitalised patient cases based on the patients' characteristics and hospitalisation characteristics. To contrast with the hospitalised patients we purposively selected 10 patient cases that were quite similar to the hospitalised patient cases but without hospitalisation in the last three month of life, in order to learn more about avoidability. This resulted in 59 in-depth interviews with 26 GPs, 18 family carers and 15 nurses.

In the Netherlands, palliative care is generalistic in nature, which means that GPs and nurses are responsible for the palliative care of patients living at home. GPs have mostly known their patients for a long time and often collaborate with nurses.[18] Early in the disease process, nurses may provide the patient and their family with advice, instruction and information, which is often limited to five hours, on average, in the total illness process.[18] Nursing care to help with daily activities in the daytime can generally be provided up to a maximum of four hours a day. If the life expectancy is less than three months, night care can also be provided for eight hours a day. Additional specialised nursing care is available for technical care such as a syringe pump or infusion therapy. All professionals have the possibility to consult a specialised palliative care team when necessary.

Data collection

Of the 59 in-depth interviews, 54 were held face to face at the preferred place of the respondent and five were held by telephone. The interviews lasted 60 minutes on average. The interviews started with a ‘grand tour’ question: “Tell me about the patient’s situation in the final three months of life for whom the GP filled in the questionnaire”. In the hospitalised patient cases, the interviewee was asked to talk about the circumstances surrounding the hospitalisation and about how hospitalisation could have been avoided or what would have helped the patient to stay at home. GPs and nurses were also asked about other recent cases where they thought that hospitalisation could have been avoided and, in contrast, about patients who were not hospitalised in the last three months of life. A short interview report with the main findings and a description of the respondent’s environment was written up after each interview. Recruitment of respondents was stopped after data saturation was reached. The in-depth interviews were conducted by a nurse scientist who has 15 years’ experience with qualitative research (MDK).

Analyses

The interviews were recorded, transcribed verbatim and then read thoroughly by the first researcher (MDK).[19] The coding scheme was inductively derived from the content of the interview transcripts. This was supported by the software program Atlas-ti. The codes were categorised into key themes that gave answers to the research question.[15] For each theme we looked at the perspective of the GPs, the nurses and the family carers. The key themes concerned key strategies, which may be positively or negatively related to hospitalisations at the end of life. This qualitative analysis process was discussed step by step with one of the co-authors (HRP), a sociologist with a nursing background who has 15 years’ experience in qualitative and palliative care research. Peer review was conducted by all authors; BS has 40 years’ experience as a general practitioner and in palliative care and AF (a sociologist and nurse), BO (a health scientist) and LD (a sociologist) all have more than 15 years’ experience in qualitative and palliative care research.

Ethics

A study protocol was approved by the Ethics Board of the VU University Medical Center Amsterdam. Before the start of each in-depth interview, the respondent was told that participation was voluntary, that the transcripts would be anonymous and that confidentiality was assured. After that, an informed consent form was signed by the respondent.

Results

Characteristics of respondents (table 1)

The mean age of the 26 GPs interviewed was 50 (range 32-64). About a quarter of them were female. Of the 15 nurses interviewed, the mean age was 45 (range of 24-57), most were female and about half of them worked in a highly urbanised environment. The mean age of the family carers interviewed was 59 (range 44-82), most of them were female and three quarters of them were the patient's partner. Of the 30 patient cases being discussed in the interviews, the mean age of the patients was 73 (range 49-97), one third of them were female, three quarters of them died of cancer.

Table 1. Characteristics of GPs, nurses, family carers and patient cases

	GP (n=26) %	Nurse (n=15)%	Family carer (n=18)%	Patients' cases (n=30)%
Mean age (Range)	50 (32-64)	45 (24-57)	59 (44-82)	73 (49-97)
Gender, female	27	93	83	30
Urbanisation level				
Very high to high	42	34	44	40
Relation to the patient				
Partner	x	x	72	x
Son/daughter	x	x	22	x
Friend	x	x	6	x
Cause of death, cancer	x	x	x	73
Hospitalised	x	x	x	67

Five key strategies

The interviews with GPs, nurses and family carers revealed the complexity of patients' situation, which included the difficulty to identify that death approaches, the complex disease trajectory, the psychosocial circumstances and the communication between professionals. From these complex patient cases, five key strategies emerged that could help avoid hospitalisation: 1) marking the approach of death, and shifting the mindset; 2) being able to provide acute treatment and care at home; 3) anticipatory discussions and interventions to deal with expected severe problems; 4) guiding and monitoring the patient and family in a holistic way through the illness trajectory; 5) continuity of treatment and care at home. The five strategies are clarified in more detail below.

1. Marking the approach of death, and shifting the mindset

From the interviews with GPs, nurses and family, it emerged that to avoid hospitalisation physicians had to have concluded and clearly communicated that the patient had a short life expectancy. This led to a huge shift in the mindset of patients, family carers and professionals, which often needed some time to become a full awareness. This shift in the mindset gave a different view of treatment in the hospital, and then the benefits and burden of treatment in the hospital were weighed up in a different way. As long as there was a glimpse of hope of a cure or improvement, the burden of being in the hospital was taken for granted, but when improvement or cure could no longer be achieved then staying at home with the family became more important. When community nurses were involved, they felt their role was to reiterate and explain what had already been said about the incurability and short life expectancy to help the patient and their family develop a full awareness of the new reality, which was that no cure was possible and the end of life was approaching.

Interviewer: "Why is it necessary to say explicitly that someone is incurably ill?
Nurse: Well, of course it is necessary for the awareness and eventually for the acceptance, when that comes. Because of course people will otherwise… well ultimately they want to keep looking for something that will make them better. And that can get very difficult because that something is no longer an option."
(Case 6, Nurse, female, age category 45-50)

GPs often found it difficult to recognise that death was approaching, and when this was not clear then hospitalisations seemed less avoidable. Sometimes the physician had communicated that death was approaching but the patient or the family did not make a shift in the mindset acknowledging that death was approaching.

Interviewer: "What exactly did the specialist tell you and your husband in the hospital?"
Family carer: "That it was malignant, that they couldn't cure it, only slow it down."
Interviewer: "What did you expect from the hospitalisation? Did your husband have certain expectations?"
Family carer: "Well, really, you could really say he kept on hoping right up to the end that he might be cured. You know, just like my youngest daughter, she was also saying that you never know, do you?"
(Case 5, Family carer, female, age category 65-70)

For some patients or their family, it was important to know that everything was being done and therefore they went on with all possible treatments in the hospital; only when it finally became clear that no improvements could be achieved were they able to accept that death was approaching. One GP talked about a situation in which the patient and the family were not able to make a shift in the mindset to acknowledge that death was approaching. In her opinion, a shift in mindset was needed to avoid hospitalisation in order to have a good farewell. However, if patients and their family did not want to make a shift in their mindset, she accepted that and then treatment in the hospital continued but was appropriate from the perspective of the patient and the family.

GP: "It was impossible in this patient's case. It simply never switched. It didn't switch for them, even at the very end."
Interviewer: "You say that it's also important for the family to make that switch."
GP: "Of course you want to grow towards it together, I reckon, towards ... So there's that aim, I think. Growing together towards a fine death where everyone still has the feeling that what had to happen happened. You can say farewell to another. But of course you need to shift into a different mindset for that. Otherwise it's not possible. And this gentleman was so hyperactive in his delirium as well and mean to his wife so that was a difficult situation at home too. Then you can't just suddenly say, it's delirium and that could mean something is up, something that can't be treated properly, because we don't know what's causing this, and now we all have to join in that nice dying process - well of course that won't work. That switch couldn't be made.(…) He was admitted to hospital; I believe a lung X-ray was made and they did some blood tests. That showed that it was not at all clear what was causing the delirium, but things were pretty bad. Poor blood labs, very poor kidney function. Very high inflammation rates in the blood. So all in all, very poor physical condition. And when the family heard that, they said well okay, the time has come. He won't be getting better, and then he was put into a separate room and the family had about one day in which to say farewell and that was really quite good. I don't think that would have been possible at home."
(Case 11, GP, female, age category 40-45)

In addition to the initial discussion with the patient that he or she was incurably ill and that life expectancy was limited, additional discussions later on in the illness trajectory could help in making a shift in the mindset to acknowledge that death was approaching and that hospitalisations were mostly not desirable or appropriate. Other marking moments to discuss these issues were when there was a functional decline, symptoms accumulated or the patient became more bedbound. At these points it could be seen that the illness was becoming more severe and death was closer. For very old patients, it was difficult to hold timely talks about end-of-life issues. On this subject, some ideas arose from the interviews, such as talking about end-of-life issues with all frail patients, all patients aged 80 and older, or when nursing care at home starts. However, for some patients the changes in their condition came unexpectedly fast, and the limited life expectancy and care wishes at the end of life were eventually discussed only shortly before dying. Then it was difficult for patients and their family to make the shift in the mindset to acknowledge that the end was approaching and consequently hospitalisation was difficult to avoid in the case of acute or accumulating problems.

2. Being able to provide acute treatment and care at home

In several patient cases, there was an acute symptomatic problem for which the patient was hospitalised. GPs said that it was often difficult to avoid hospitalisation when the acute situation arose, especially in the out-of-hours service when patients had severe symptoms or family who did not know what to do.

GP:"That's a bit more difficult when you're on call, because of course you sometimes get questions like that on call, 2 o'clock on a Saturday night. Well if you, if you have to arrange something then, and often you have the entire family in the room so something has to be done there and then. And then you're sitting there as a doctor who is a complete stranger with a patient you don't know at all, whose prior history you don't know, and then you have to start from scratch at that point; I find that… I don't enjoy that, I find it very difficult to work like that and there is so much pressure being put upon you and then sometimes you don't really have any choice other than to get someone admitted to hospital just to be rid of that pressure."
(Case 16, GP, male, age category 46-50)

In acute situations, GPs, and family carers too, said that it was important to sit down and take time to discuss all possible options for treatment at home or in the hospital. In the case of patients who were not hospitalised, we noticed that in acute situations everything fell into place; the patient and family carers knew what to do. For acute treatment in the last days of life, the comfort of the patient was essential and sometimes when there were severe symptoms in the last days of life, palliative sedation was seen as a good option. One GP, for example, said that he sometimes used an intermittent palliative sedation to have a timeout.

GP:"Well, then you are the bedrock they can always fall back on, when they get into a panic and think we're not going to cope. But I explain that they can always call me, day or night. I have the tools, I can apply sedation for instance, simply to create a timeout, to say listen, we'll calm things down. Let their patients and their family pause for breath so that they can once again accept the unacceptable and go down that road."(…) "You can give yourself a break and say, well, I'm going to intervene here and then we'll see later what to do next. Time is a good partner, you know."
(Case 7, GP, male, age category 55-60)

To avoid hospitalisation for the purpose of continuous observation, some nurses said GPs and family carers was not always known that they could respond rapidly and provide night care, especially when the patient was already known by the home care organisation.

3. Anticipatory discussions and interventions to deal with expected severe problems

One of the strategies for avoiding hospitalisations was anticipatory discussions about medical decisions at the end of life and interventions to deal with severe problems in the illness trajectory. After it had been marked that death was approaching, and sometimes before that point, some GPs or patients initiated anticipatory discussions about medical decisions at the end of life. These discussions about medical decisions dealt with the patients' preferences in the case of resuscitation, euthanasia or palliative sedation. GPs and nurses said in the interviews that whether or not to hospitalise was not always discussed directly, but it was touched on indirectly as the preference of patients and their family for staying at home was discussed. Patients who were not hospitalised had often expressed the explicit wish to stay at home several weeks before death.

GPs and nurses said that they had often anticipated severe problems such as pain or acute bleeding and what patients and their family could do in such a situation.

Nurse: "We get a client at home, often they've come from the hospital because that's where the tests are done. Then we get information transfer from the GPt making clear that this is a terminal client. Well, often we'll talk then about what we should do if something should happen. What if someone should have a haemorrhage for example or become unwell. Well, then it's useful to know if we should call the emergency number and then go to the hospital. Or should we consult a out-of-hours general practice, stay at home and do what we can to make things more bearable?"
(Case 13, nurse, female, age category 35-40)

Mention was made less often of professionals anticipating other symptoms that may accumulate or exacerbate in the illness trajectory. Therefore, it was seen that patients were hospitalised for problems other than pain or acute bleeding, such as respiratory problems. However, it was not possible to anticipate every symptom.

GP about a male cancer patient (age category 70-75) who had two acute hospitalisations because of a dyspnoea and delirium.
Interviewer: "How could hospitalisation have been avoided?"
GP: "Well, by going through all the possible scenarios, but at the same time that's not very realistic. At any rate, because there are so many different things that could be done, but some things, well perhaps you could have done them earlier."
(Case 17, GP, male, age category 40-45)

In addition to anticipating severe symptoms, other interventions were also mentioned in the interviews aimed at preventing hospitalisation after a severe acute situation. Firstly, the GPs sometimes gave their personal phone number. In addition, nurses said that they also gave the number of the nurse in charge if more observation of the patient's situation was needed. Secondly, registration of the patient's preferences in the medical chart of the out-of-hours general practice and also documentation of the short life expectancy were considered to be important anticipatory measures for acute situations outside of normal practice hours. Thirdly, if severe symptoms were expected, some GPs put some extra medication in the refrigerator and gave an explanation about how and when to use this. Also, some nurses asked the GP to prescribe ‘as needed’ medication.

4. **Guiding and monitoring the patient and family in a holistic way though the illness trajectory**

In the interviews, GPs, nurses and family carers talked about the importance of guiding and monitoring because often unexpected problems could arise in the illness trajectory; if these problems were recognised early and there was adequate relief then a hospitalisation could be avoided.

Family carer about her deceased father (not hospitalised) and husband (hospitalised).
“The morphine made my father very calm. It made him sleep an awful lot. But if he got too much morphine, you saw exactly the same as with my husband. Then he would become restless and then he would really get out of control and panic, and it was such a fine balance between those two. That was really my experience with both of them. Because it's about knowing someone really well and knowing how he responds to medicines, (…) and simply because you (the nurse) are always there and see what's happening.”
(Case 28, family carer, female, age category 50-55)

For several GPs and nurses, guiding and monitoring meant working in a team that led the patient and the immediate family through the illness trajectory and explained step by step what was happening in the illness trajectory. Some professionals talked about the holistic way in which patients were guided and monitored with regard to multidimensional physical and psychosocial problems that could change slightly in patients and their family, and then hospitalisation could be avoided. From the interviews it emerged that nurses, more than the GPs who were interviewed, were alert to the psychological changes in patients and their family, and worked to strengthen coping mechanisms. Several professionals talked about an intuitive process of guiding and monitoring that needed intensive contact with the patient in order to prevent acute problems.

GP: “If they suddenly get a lot more symptoms all at once, then a lot of people become unsure. So - as a doctor - you try to give these people, for good or for ill, something to hold onto or offer them something, you want to do that to give them some support.”
Interviewer: “What do you want to offer them?”

GP: "Well, that's a good question. Well, something that gives them the feeling that they may be getting some support or at any rate that they are being taken seriously and that they may be able to have some part in this. To enter that process together, so that they are not left alone, see, and you are trying to do something to guide them through this successfully."
(Case 27, GP, male, age category 30-35)

Asked in the interviews about the patient's situation as a whole, sometimes it emerged that professionals did not see the complete picture of their patient. One such example was a patient case where the GP, nurse and family carer were interviewed: it turned out that the nurse, who gave a lot of attention to helping the patient prepare for and accept death, did not give much attention to the partner's sleeplessness due to the fact that the patient was very restless at night. The reason for hospitalisation in the end was the burden on the partner caused by sleeplessness. In the case of this patient, the GP only had contact with the partner by phone when the partner asked for help, which were often questions about practical aspects, but this GP did not visit the patient and partner to guide and monitor them.

Finally, nurses did not always start the guiding process because some family carers wanted to care for the patient up to the end of life and thought that they did not need the care of a community nurse. Some family carers and also some GPs did not know about the supportive competences of the nurse and that supportive nursing care could start early in the illness trajectory. Nurses said that it was very important for them to start guiding and monitoring patients early in the illness process to in order to prevent acute somatic or psychosocial problems that could be a reason for hospitalisation. Some nurses and family carers talked about their concerns when too many nurses cared for a patient and the nurses were not sufficiently qualified: nurses with insufficient training could miss important observations and then fail to guide the patient in an optimum manner.

5. Continuity of treatment and care at home

Continuity in treatment and care was considered important in following the illness trajectory but so was continuity in the people acting as physicians and nurses. GPs said that after the medical specialist had marked the approach of death, they wanted to have the lead instead of the medical specialist. Therefore what was needed was one GP and a small number of nurses to provide continuity of treatment and care. Together with the nurses, they wanted to build up a relationship of trust that was a prerequisite for anticipating, guiding and monitoring properly.

GP about a restless man with multimorbidity whose hospitalisation was initiated by a hospital specialist.
GP: "I do feel he was the victim of a lack of continuity care by the GP practice. Otherwise things might have gone differently."
Interviewer: "Oh? What do you think might have gone differently?"
GP: "You see a difference, then you can take anticipatory measures to deal with what might happen. You've built up a relationship and you know what someone's cognitive status is and how that has changed and then you can take proactive measures, so consult the psychiatrist proactively and get involved, and now I didn't get involved because I simply didn't know what his condition was. And that happened in the secondary care without them getting a GP involved."
(Case 2, GP, female, age category 30-35)

Several patients were treated continuously during the illness trajectory, receiving treatment for pain, nausea or other symptoms or care for a wound or urinary catheter. Continuous interaction between the GP, nurse and family carer was needed for this treatment and care in order to prevent acute severe symptoms or other problems that could lead to acute hospitalisations.

Some patients needed a short hospitalisation for treatment of symptoms, such as for a stent implantation, lung puncture or ascites puncture. If patients needed a short treatment in the hospital, as some GPs explained, it was necessary to stay in dialogue with the medical specialist and discuss when to stop this treatment in the hospital, or go on with this treatment at home in order to prevent long hospitalisations. For other treatments, such as ascites punctures, infusions for antibiotics or blood infusions, it was not always necessary to go to a hospital. Some nurses said that these relatively simple treatments could be provided at home more often if the GP and patient were aware of all the competencies of community nurses. Treatment was often discussed as a technical option that did not result in a heavy physical burden for the patient, but the emotional burden of the treatment in the hospital and the fact that as a result the patient spent less time with the family was less likely to be discussed. One family carer thought that if the emotional burden of the stent implantation had been discussed then his wife would have refused this treatment because she was very anxious about it.

Family carer about the hospitalisation of his wife.
"She was really dreading that, so perhaps she would have said because of that, well I don't need this anymore. That's the impression I got."
(Case 10, family carer, male, age category 80-85)

Continuity of treatment and care became more intensive when death became immanent. Regular observation was required especially if patients then needed a syringe pump for medication, because adjustments of medication based on observations might be necessary to treat the symptoms. In addition, nursing care for bathing the patient was often given at the end of the illness trajectory and night care could also be provided, in both cases to relieve the burden of the family carer, which helped the patient to remain at home.

Nurse about a patient who was not hospitalised.
"Then the daughter said, I'm not getting enough sleep at the moment, and that palliative package (extra palliative care from a nurse) had been there for a while by then. Because it had already been applied for by the GP, saying that this man wants to stay at home and eventually he'll simply need all the care that will let him, in his situation, stay at home and also die at home, if possible."
(Case 24, nurse, female, age category 40-45)

Interrelation between the five key strategies

The interviews revealed not only the five key strategies for avoiding hospitalisation but also an interrelation between these key strategies. The starting point of these five strategies was marking the approach of death, which often led to a huge shift in the mindset of patients and their family, and it often took time for a full awareness of this new reality to develop. From that point the benefits and burden of hospitalisations were weighed up in the light of the short life expectancy. Then staying at home, the quality of life and comfort of the patient became more important. After marking the approach of death, the process of anticipating problems, guiding and monitoring in a holistic way and ensuring continuity in treatment and care started, and gradually became more intensive up to the end of life. When interviewees were asked about how strategies could be optimised to avoid hospitalisation, then it became apparent these key strategies could be improved if implemented in a less fragmented way.

To illustrate the interrelation of the five key strategies, three example cases are presented (Boxes 1, 2 and 3). In all three cases there was an acute situation, and in two of the cases the patients were hospitalised (Cases 1 and 2). In Cases 1 and 3 we see that it was marked that death was approaching at the point when the medical specialist called the GP to say that there were no effective curative treatment options. This was discussed with the patients but neither patient made a shift in mindset at that moment to acknowledge that death was approaching. In Case 1, the GP anticipated dying but not the illness process as a whole in which dyspnoea in the lung cancer patient could be expected. After that moment the GP was reactive and waited until he was needed. In Case 3 the GP guided and monitored the patient and also offered the continuing support of a nurse; none of this was provided in Case 1. In the embedded continuous care by the GP and nurse in Case 3, it was a small step for the family carer to call the nurse and later on the GP in the event of an emergency.

In Case 2, anticipating acute situations and guiding patient and family though the illness process was difficult because the patient did not want to look at the future, even in his old age. While giving continuous care, the community nurse monitored the patient. However, the nurse did not discuss the patient's functional decline and refusal to eat and drink with the GP; this could have been another moment for marking the approach of death and a starting point to anticipate the end of life. In Case 2, the family carer thought afterwards that hospitalisation could have been avoided when the acute situation arose if the GP had sat down and discussed all possible options for staying at home.

Box 1. Case 1, woman with lung cancer, aged 57

The patient is divorced and has two sons aged about 20, one of whom still lives at home. She runs her own business.

Three months before the patient's death, the GP receives a phone call from the specialist saying there are no more curative treatment options.

The next day, the GP pays a visit to the patient and at the patient's request they discuss how the GP can assist her when dying.

The GP does not talk about the options for palliative care for the rest of the disease trajectory, nor do they discuss nursing care as the GP judges that the woman and her sons will be able to cope over the next while.

The GP tells the woman she can always call him if anything comes up and gives her his mobile number.

Afterwards, the GP calls the woman occasionally and asks her if there is anything he can do.

The woman wants to continue working for as long as possible, despite her fatigue.

The son who lives at home is pleased his mother is taking such a positive view of things and he hopes to keep his mother with him for as long as possible.

Three days before she dies, the mother suddenly feels severe tightness in the chest and she calls the medical specialist, with whom she is on good terms.

The woman is admitted to hospital for two days, where she receives morphine and oxygen.

Then she is sent home with the aim of letting her pass away at home.

The next day, she dies in the presence of her two sons.

Box 2. Case 2, man with dementia, aged 88

The patient lives at home with his younger wife who is still working as a doctor.
The patient has been receiving nursing care twice a day for two years.
The nursing staff help the man wash, get dressed and take his medication.
The patient's condition is gradually deteriorating; recently he has stopped really wanting to eat or drink anything and he spends most of the day in bed.
The GP did make some attempts to discuss the patient's death with him and his wife but they wanted to leave the future to God.
One afternoon, the community nurse finds the patient on the floor and she diagnoses hemiplegia.
The GP comes at once and discusses the situation on the phone with the man's wife.
The wife comes straight home from her work and agrees that her husband has hemiplegia; it is difficult to communicate with him and he is confused.
The GP has already left but is called on the phone and together they decide to admit the patient to hospital.
The woman hopes they may still be able to do something for him in the hospital.
Rapid admission is important after a CVA.
The patient is admitted to hospital and dies there two days later.
When the wife was asked in the interview what she would have done if she had been the GP in charge, she said:
"If you want to discuss this difficult problem, you need to allow more time for it. I would talk to the people separately and say that there is a really high risk of this ending in death and the benefit for you if you keep him at home and immediately increase the level of care is that you remain in your own surroundings and he can eventually pass away in his own surroundings. (...) We could do that just as well here at home as we could in the hospital or a hospice or whatever."

Box 3. Case 3, patient with prostate cancer, aged 78

The patient is a businessman. He lives with his wife who is in the early stages of dementia and has an adult daughter.

The patient is told four months before his death that he has metastatic cancer.

Afterwards, he takes part in a medical trial that does not require hospital admission.

The daughter experiences it as a big burden because her mother has incipient dementia and does not really understand her husband's illness.

The GP finds it impossible to discuss the approaching death with the patient during the medical trial. The GP does pay regular visits because the informal carers are finding it so tough and he expects the patient to develop severe symptoms.

The nursing staff drop in every day because there is a catheter.

One month before the patient's death, the specialist calls the GP to tell him that the medical trial with chemotherapy is being stopped because his blood lab values suggest the cancer is increasing.

Then the patient himself takes the initiative to discuss with the GP what they can expect from one another, and they talk about how to achieve a good death. The patient says he may want palliative sedation at the end of his life.

The GP and nurse both give their mobile numbers so that they can be called in the event of an emergency.

At one point, the patient starts vomiting a great deal. The daughter panics and calls the community nurse, who comes at once. The GP is called as well. Together, they manage to resolve the panic situation.

Three days before his death, it seems as if the patient may be getting an intestinal obstruction; he is in a great deal of pain but he does not want to go to hospital. They start administering morphine to stop the pain and later he is sedated.

The patient dies at home in the presence of his family.

Discussion

This qualitative study looked at avoidable hospitalisations from the perspectives of GPs, nurses and family carers. We found an interrelation between five key strategies that can help in avoiding hospitalisation. The key strategies were: 1) marking the approach of death, and shifting the mindset; 2) being able to provide acute treatment and care at home; 3) anticipatory discussions and interventions to deal with expected severe problems; 4) guiding and monitoring the patient and family in a holistic way through the illness trajectory; 5) continuity of treatment and care at home. In acute situations it was important that these five key strategies were provided in an interrelated way, otherwise this could result in hospitalisation at the end of life.

A strength of this study is that in-depth interviews are included from the perspectives of GPs, nurses and family carers. This study provides new insights into the avoidability of hospitalisation at the end of life of patients who reside at home. It has limitations in the generalisability and external validity of the results. However, the findings of qualitative studies are meant rather to help understand processes and practice,[20] in this study namely the processes and practice relating to hospitalisation and its avoidance at the end of life. Another limitation of this interview study is the potential recall bias of respondents who were asked about a deceased patient one year to one and a half years after death. To overcome recall bias, GPs and nurses were also asked about other recent patient cases and about what they do in general in such cases, such as how they anticipate hospitalisations in general.

This study presented interrelated strategies for avoiding hospitalisations from the perspective of GPs, nurses and family carers. The starting strategy is that it is necessary to mark the approach of death and to communicate that there are no effective curative treatment options. However, as it is suggested in this study and also shown in other studies, it is often difficult to recognise that death is approaching, especially for non-cancer patients.[21] For professionals, one way of marking the approach of death is is to ask yourself the ‘surprise’ question “Would you be surprised if this patient died in the next year?”, which is part of the internationally renowned Gold Standards Framework (GSF).[22] The GSF and the Radboud indicators for palliative care needs (RADPAC) also provide clinical indicators for physicians to mark that the patient is in a situation in which the end is approaching.[22;23] In addition to this, this study described that it is important there is a shift in the mindset to acknowledge that death is approaching. However, some patients and family do not to make a shift in the mindset and deny that death is approaching. Research suggests that patients' denial may have a protective effect on emotional and social outcomes in the quality of life.[24] Therefore, it is recommended that patients are asked whether they prefer to have open communication about the end of life. Irrespective of the patient's preference for open communication about the end of life, guiding and monitoring by both GPs and nurses are needed in order to be alert to accumulating or acute symptoms in the illness trajectory in the last months of life.

Another strategy in the interrelated strategies that this study has presented is the anticipatory discussions and interventions to avoid hospitalisations. One form of anticipatory discussions is advance care planning, which includes discussions about medical decisions at the end of life. Other studies have indeed shown that holding advance care discussions about medical decisions at the end of life results in fewer hospital deaths.[25;26] Another aspect of this strategy includes the anticipatory interventions. Other studies also show that anticipatory interventions such as the availability of 'as needed' medication [28] or information transfer to the out-of-hours GP cooperative [28] can be successful in reducing hospitalisations at the end of life.

The end-of-life care pathway of the Royal College of General Practitioners and the Royal College of Nursing includes several elements of palliative care that are comparable to the strategies as presented in this study, such as identifying that the end of life is approaching, discussions as the end of life approaches, assessment, care planning, review, and coordination of care.[29] In addition to this, our strategies can also be recognised in multidimensional interventions provided by multi-disciplinary teams with highly trained nurses, which have been shown to reduce hospitalisations at the end of life.[30;31] These interventions consisted of timely discussion with the patient and family about their preferences and what might happen at the end of life, and proactive monitoring. These multi-disciplinary teams for palliative care show the importance for GPs and nurses of working in a team. In the Netherlands, new projects have started for palliative care at home (PaTz), in which GPs have rediscovered cooperation with community nurses while before some GPs did not even know about the possibilities of early supportive nursing care.[32]

Conclusion

This descriptive study found five key interrelated strategies for avoiding hospitalisation, namely marking the approach of death and shifting the mindset, being able to provide acute treatment and care at home, anticipatory discussions and interventions to deal with expected severe problems, guiding and monitoring the patient and family in a holistic way through the illness trajectory, and continuity of treatment and care at home. Both GPs and community nurses have their own professional competencies for applying these strategies. Therefore it is recommended that for all patients residing at home, GPs and community nurses should work together as a team from the moment that it is marked that death is approaching up to the end of life. As the five key strategies presented here include several elements of a palliative care approach, we may conclude that palliative care provided by GPs and community nurse can help avoid hospitalisation.

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Chapter 7

Generalist primary and palliative care is associated with few hospitalisations in the last month of life

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Abstract

Background

Reducing hospitalisations in the last phase of life can be seen as an indicator of good palliative care. The aim of this paper is to study the association between provision of primary and palliative care at home and hospitalisations in the last phase of life in the Netherlands, a country with a generalist palliative care model.

Methods

We conducted a cross sectional survey among Dutch general practitioners (GPs) on their most recent patient that died non-sudden. Of 1601 eligible GPs, 598 responded (37%). Questions were asked on (timing of) hospitalisation and on elements of primary care, generalist palliative care and consultation of specialised palliative care. The relation between these elements and hospitalisation were tested controlling for patient characteristics.

Results

Two primary care elements were related to both not being hospitalised in the last week of life and not being hospitalised in the last month of life: having more GP visits two to three months before death (OR=2.64 and OR=2.37) and information transfer to out-of-hours GP services more than one week before death (OR=2.02 and OR=1.64). The two palliative care elements studied were only associated to not being hospitalised in the last month of life: recognizing that death was near earlier (OR=1.75) and having palliation as the main treatment aim (OR=2.34). Consultation of a specialised palliative care professional in the last three months of life, were not found to be associated with not being hospitalised .

Discussion

Our results show that generalists, especially GPs, can play an important role in providing palliative care at the end of life, when looking at hospitalisations as indicator of quality. This suggests that a generalist palliative care model is feasible.

Introduction

Hospitalisations in the last phase of life may be related to poor quality of palliative care at home. Taking into account that not all hospitalisations can be avoided, Earle and coiselleagues[1] developed a quality indicator for cancer patients defining that quality of care is poor when more than 4% of all patients are hospitalised more than once in the last month of life. In a study among GPs in four European countries was found that The Netherlands, Italy and Spain met this performance standard (0.3%, 3.1% and 4.0%). Belgium had a score of 5.4%.[2]

There is evidence that 'specialist palliative home care teams' reduce transfers to the hospital in the last phase of life, length of hospital stay and hospital deaths.[3-9] Furthermore, a Cochrane review about the effectiveness of home palliative care services including 23 studies in different countries and mainly about cancer patients, showed that home specialist palliative care increases the chance of dying at home.[10] These studies provide evidence that specialist palliative care is effective in reducing hospitalisations at the end of life and increasing home deaths. However, it has been suggested that to realise sustainable palliative care for home dwelling patients it is necessary to give a strong role to generalists in palliative care.[11] In a generalist palliative care model the focus is on care delivered by generalist clinicians. The general practitioner (GP) or hospital physician remains the treating physician in the palliative and dying phase, and can consult a specialist or specialized team in palliative care in complex cases.[11]

The Netherlands is one of the countries that has such a generalist palliative care model.[12] For patients at home GPs are key professionals in providing care at the end of life; together with, when needed, a district nurse. They can provide primary care such as home visits, specialised nursing care, nursing care at night, and transferring information to an out-of-hours GP service. More specific elements of palliative care that they can include in their care are recognizing timely that death is near, and having a palliative treatment aim. Finally, if necessary, they can consult a palliative care consultant or team.

Earlier studies have shown that elements of a palliative care approach in Dutch primary care, such as timely identification that death is approaching, palliation being an important treatment aim and awareness of the patient's preferred place of death are associated with dying at home.[13-14] Furthermore, it was found that transferring information from the responsible GP to out-of-hours GP services was associated with few hospitalisations.[15] In addition, De Roo and colleagues[2] found in a comparative study in The Netherlands, Belgium, Italy and Spain that when GPs provided palliative care this decreased the chance that a patient was hospitalised more than once in the last month of life. However, none of these studies looked at the relation between a combination of elements of primary and palliative care and hospitalisation in the last period of life. Therefore, the aim of this paper is to study the association between provision of primary and palliative care at home and hospitalisations in the last phase of life in the Netherlands, a country with a generalist palliative care model.

Methods

Design and study population

We conducted a cross sectional survey among Dutch general practitioners (GPs) about their most recent deceased patient whose death was non sudden. A random sample of 2000 GPs was selected from the population of 8896 registered GPs in the Dutch “Medical Address book” of 2010. 1200 GPs were sent a questionnaire on their most recently deceased patient whose death was non sudden and who was hospitalised in the last three months of life and 800 GPs were sent a questionnaire on their most recent deceased patient whose death was non sudden and who was *not* hospitalised in the last three months of life. 238 GPs were not eligible because they did not work as a GP in a GP practice at the time of data collection and 161 were not eligible because they did not have a patient case that met the criteria (ie. patient who died non sudden in the past year and who was or was not hospitalised in the last three months of life). This resulted in 1601 eligible GPs of whom 598 responded (37%). After checking the questionnaires, five patient cases did not meet the criterion of a non-sudden death and were removed from the sample, leaving 593 patient cases. For this paper we excluded data of 96 patients who lived in a residential home or another institution from the analysis, since the palliative care provision and need for hospitalisation can be different in an institution with 24-hours care. This resulted in 497 patient cases: 271 cases about a patient who was hospitalised from home in the last three months of life and 226 cases about a patient who was not hospitalised in the last three months of life. The study protocol was approved by the Ethics Board of the VU University Medical Center.

Measurement instrument

Written questionnaires were developed using relevant literature and in-depth interviews with five GPs. A draft was tested among 14 GPs and comments were incorporated in the final version of the questionnaires. Next to patient and GP characteristics, both questionnaires included elements of primary and palliative care. A hospitalisation was defined as admission to a hospital for at least one night. In the questionnaire for patients who were hospitalised questions on time of the hospitalisation in the last three months of life were asked. When the patient was hospitalised more than once in the last three months of life, we asked the GP to fill in the questionnaire for the last hospitalisation before death.

Data analysis

For looking at the primary and palliative care elements in relation to hospitalisations univariately patients were divided into 4 groups: not hospitalised in last three months of life (n=226), hospitalised in month two to three before death (n=77), hospitalised in week two to four before death (n=113), and hospitalised in the last week of life (n=81). Differences in patient-, physician-, and care characteristics between these 4 groups were tested with pearson's chi-square test. For the multivariate analysis we looked at hospitalisations in two time periods: hospitalisation in last week of life (n=81) versus no hospitalisation in last week of life (n=416), and hospitalisation in last month of life (n=194) versus no hospitalisation in last month of life (n=303). For each of these two analysis variables that assessed the care received before the hospitalisation were included in the analyses, to be sure that they could have influenced hospitalisation. For instance in the analysis for hospitalisation in the last *month* of life the variable 'GP visits 2nd – 4th week before death' was not included. We conducted stepwise backward regression analysis, manually removing the variable with the highest p-value per step of the analysis. In these analyses patient characteristics (age (<65, 65-79, ≥ 80), sex, cause of death (cancer versus no cancer), and multi-morbidity (one disease, two diseases, three or more diseases) were forced in the analysis to control for patient characteristics.

Results

Patient and GP characteristics according to hospitalisation

Table 1 shows patient characteristics for the four hospitalisation groups: no hospitalisation in the last three months of life, (last) hospitalisation two to three months before death, (last) hospitalisation two to four weeks before death, and (last) hospitalisation in the last week of life. There were no significant differences in age, multi morbidity and having an informal care giver between patients in the four different hospitalisation groups. For the other patient characteristics measured there were differences. Patients who were hospitalised in the last week of life were more often male, more often died of stroke and less often died of cancer.

Table 1. Patient characteristics according to hospitalisation in the last three months of life* (rounded %)

	No hospitalisation n=226	Hospitalisation in month 2 to 3 n=77	Hospitalisation in week 2 to 4 n=113	Hospitalisation in last week n=81	*P* value
Age					
<65	29	22	36	36	ns
65-79	38	51	42	37	
≥80	33	26	22	27	
Gender, male	50	58	54	68	0.043
Cause of death					
Cancer	71	70	74	61	0.008
Cardiovascular	12	16	13	15	
Respiratory	2	0	3	5	
Stroke	5	7	8	17	
Other	10	8	3	3	
Multi morbidity					
No	67	64	57	53	0.099
2 diseases	17	16	23	31	
3 or more diseases	16	21	20	16	
Informal care giver					
No	3	5	4	6	ns
Yes, living elsewhere	62	71	73	73	
Yes, living with patient	35	23	23	21	

*Focus on most recent hospitalisation before death; less than 1% missing cases

Table 2. GP characteristics according to hospitalisation in the last three months of life* (rounded %)

	No hospitalisation n=226	Hospitalisation in month 2 to 3 n=77	Hospitalisation in week 2 to 4 n=113	Hospitalisation in last week n=81	*P* value
Age					
<45	32	30	30	25	ns
45-54	39	46	37	33	
≥55	29	25	33	42	
Gender					
Male	56	57	52	59	ns
Working hours					
80-100%	32	43	34	33	ns
Less than 80%	68	57	66	67	
Years working as GP					
<10	24	22	21	23	ns
10-19	34	46	37	34	
≥20	42	33	42	44	
Practice size					
<1500 patients	12	16	13	13	ns
1500-2000 patients	17	23	25	20	
>2000 patients	71	61	62	67	
Received palliative care training	55	53	54	51	ns

* Focus on the most recent hospitalisation before death; less than 1% missing cases

Table 2 shows that there were no significant differences in GP characteristics between patients in the four different hospitalisation groups.

Elements of primary and palliative care according to hospitalisation

Of the primary care elements measured, there were no significant differences between patients in the four different hospitalisation groups in the extent to which specialised nursing care or night care by a nurse were given. Differences were found for the GP related primary care elements. Three or more GP visits per month in month two to three before death more often occurred in patients who were not hospitalised or who were hospitalised in month two to three before death compared to patients who were hospitalised shorter before death (34% and 33% vs. 18% and 12%). Two or more GP visits per week in week two to four before death most often occurred in patients who were not hospitalised (61%) and least often in patients who were hospitalised in the last week of life (33%). Information transfer to out-of-hours GP services more than one week before death was more often done for patients who were not hospitalised or hospitalised in month two to three before death compared to patients who were hospitalised in week two to four before death or in the last week of life (64% and 64% vs. 51% and 37%) (table 3).

Table 3. Elements of primary and palliative care according to hospitalisation in the last three months of life (rounded %)

	No hosp. n=226	**Hosp. in month 2-3** n=77	**Hosp. in week 2-4** n=113	**Hosp. in last week** n=81	***P* value**
Primary care elements					
GP visits 2^{nd} - 3^{rd} month before death					
≥ 3x/month	34	33	18	12	<0.001
GP visits 2^{nd} - 4^{th} week before death					
≥ 2x/week	61	50	49	33	<0.001
*Specialised nursing care in last three months***					
No	48	43	50	66	ns
Only last week	29	25	23	15	
More than one week	23	32	27	20	
*Night care by nurse in last three months***					
No	58	55	68	68	ns
Only last week	28	27	27	22	
More than one week	14	18	5	10	
*Information transfer to out of hours care**					
No	24	26	41	46	<0.001
Only last week	13	10	8	17	
More than one week before death	64	64	51	37	

Table 3 (continued)

	No hosp. n=226	Hosp. in month 2-3 n=77	Hosp. in week 2-4 n=113	Hosp. in last week n=81	*P* value
Generalist palliative care elements					
*Recognizing death was near**					
>3 month before death	40	40	35	32	<0.001
2-3 months before death	40	40	24	37	
2-4 weeks before death	16	20	30	19	
In last week before death	4	0	11	12	
*Main treatment aim palliation since**					
6 months before death	32	17	13	18	<0.001
3 months before death	27	25	10	14	
1 months before death	29	38	29	21	
1 week before death	12	17	39	31	
No palliative treatment aim	1	4	10	17	
Specialist palliative care					
*Consultation of palliative care professional in last three months****					
No	78	84	81	90	ns
Only in last week	12	11	15	8	
More than one week before death	10	4	4	3	

* Focus on the most recent hospitalisation before death; less than 1% missing cases

** 226 missing cases (only asked in reminder)

*** 26 (4%) missing cases

For both elements of generalist palliative care there were significant differences for the four hospitalisation groups. That death was near, was recognised in most patients for more than one month before death, but this was the case more often in patients who were in the first two hospitalisation groups (no hospitalisation or hospitalised in month two to three before death) than in the other two groups (80% and 80% vs. 59% and 69%). Palliation was more often the main treatment aim 6 months before death in patients who were not hospitalised compared to patients who were hospitalised at some point in the last three months of life (32% vs 17%, 13% and 18%) (table 3).

Finally, table 3 shows that in a minority of cases a specialised palliative care professional was consulted (between 11% and 22%). This did not differ for the four hospitalisation groups.

Associations with not being hospitalised in the last week of life

Of all generalist primary and palliative care elements that significantly differed for the four different hospitalisation groups, only two primary care elements remained significant in the multivariate logistic regression with not being hospitalised in the last week of life as dependent variable. Patients whose GP visited them three times or more per month in month two to three before death had a higher chance not being hospitalised in the last week of life than patients whose GP visited them less often (OR 2.64). In addition, patients whose GP transferred information to the out-of-hours GP services for more than one week before death had a higher chance not being hospitalised in the last week of life than patients whose GP had not transferred information to the out-of-hours GP services or only in the last week before death (OR 2.02) (table 4).

Discussion

We found that more GP visits two to three months before death and information transfer to out-of-hours GP services more than one week before death are associated with not being hospitalised in the last week of life Widening the scope to the last month of life, in addition to more GP visits and information transfer, recognition that death is near for more than one month before death and palliation as main treatment aim for more than one month before death are associated with not being hospitalised in the last month of life. Other studied elements of primary care (specialised nursing care in the last three months of life, night care by nurses in the last three months of life), and consultation of a specialised palliative care professional in the last three months of life, were not found to be associated with not being hospitalised in the last month or last week of life.

Table 4. Associations of primary and palliative care elements with not being hospitalised in the last week and last month of life

	No hospitalisation in the last week of life*		No hospitalisation in last month of life**	
	OR (CI)	*P* value	OR (CI)	*P* value
Primary care elements				
GP visits 2^{nd} - 3^{rd} month before death				
< 3x/month	1		1	
≥ 3x/month	2.64 (1.25 –5.57)	0.011	2.37 (1.43 – 3.93)	0.001
Information transfer to out of hours care				
No or only in last week of life	1		1	
> week before death	2.02 (1.18 – 3.46)	0.010	1.64 (1.06 – 2.52)	0.025
Generalist palliative care elements				
Recognizing death was near				
≤ one month before death	***		1	
> one month before death			1.75 (1.05 – 2.89)	0.030
Main treatment aim was palliation				
≤ one month before death	***		1	
> one month before death			2.34 (1.51 – 3.64)	<0.001

* reference group: patients that were hospitalised in the last week of life (n=77); age, sex, cause of death and multi morbidity were included in the analyses as fixed variables to control for patient characteristics; recognizing death was near more than a month before death, having palliation as main treatment aim more than a month before death, and GP visits 2^{nd} - 4^{th} week before death were included in the first step of the analysis but were not remained in the final model

**reference group patients that were hospitalised in the last month of life (n=177); age, sex, cause of death and multi morbidity were included in the analyses as fixed variables to control for patient characteristics; all variables that were entered in the first step of the analysis remained in the final model

*** variables not maintained in the final model because they were not significant

Strengths and limitations

This is one of the first studies looking into associations between elements of primary and palliative care provided in a country with a generalist palliative care model and hospitalisation in the last phase of life. A strength of the study is that we were able to ensure that the care characteristics entered as independent variables in our analysis in time preceded hospitalisations, the dependent variable. This was only not possible for information transfer to GP out-of-hours services in relation to hospitalisation in the last month of life. While the number of cases in the study is substantial, the response percentage is a limitation. However, GP characteristics in our sample are similar to those of all Dutch GPs.[16] In interpreting the results it is important to realise that we divided our sample and asked one part for a case of hospitalisation and the other part for a case without hospitalisation. This might especially have had influence on not finding differences in GP characteristics with regard to hospitalisation. Furthermore, it can be argued that we did not include all elements of a palliative care approach in our study. We for instance did not include advance care planning in our analyses, although it is found before to be associated with no hospitalisations at the end of life.[13,17]

Effective elements of primary and palliative care

Controlling for patient characteristics, we found several elements of primary and palliative care provided by generalists remained associated with not being hospitalised. We found that when death was recognised more than one month before death and the main treatment aim was palliation more than one month before death, patients had a higher chance not being hospitalised in the last month of life. This result confirms that these elements which enable anticipating the last phase of life are important. Surprisingly, we did not find these associations when looking at hospitalisations in the last week of life. This might be explained by the fact that situations in which hospitalisation is considered in the last week of life more frequently are acute situations that are difficult to avoid. However, not much is known yet on the relation between acute situations and time until death. One could argue that with good anticipatory care, such as discussing in advance with the patient if he would want to go to hospital when an acute situation occurs or the availability of as needed medication at home[18], part of hospitalisations in acute situations can be avoided. Of course it can also be that closer to death more patients or relatives prefer hospitalisations.

Besides the above mentioned elements of palliative care, we found two primary care elements associated with not being hospitalised both in the last month and the last week of life: the GPs visiting the patient three times or more per month in month two to three before death and GPs transferring information about the patient to the to out-of-hours GP services for more than one week before death. Since many patients are transferred out of hours and it is found before that information transfer can reduce hospitalisations,[15] it is recommended that GPs do this systematically for their palliative patients.

It is noteworthy that the use of specialist palliative care, consultation of a palliative care professional, was not related to hospitalisation at the end of life. Consultation of a palliative care professional specifically was only used in a minority of all patient groups. This might have to do with the strong emphasis on the GP in palliative care policy in the Netherlands. In Belgium, where there is a palliative care model that acknowledges the role of the generalist care providers, but puts a stronger emphasis on the role specialist palliative home care teams[12], it was found that the involvement of these specialist palliative care teams was positively associated with home deaths while GP involvement was not.[9]

The feasibility of a generalist palliative care model

Our results show that generalists, especially GPs, can play an important role in providing palliative care at the end of life, when looking at hospitalisations as indicator of quality. This suggests that a generalist palliative care model is feasible. At the same time, the fact that we could find variation in the extent to which the different elements of palliative care occurred, shows that there is still room for improvement. It is for instance known that physicians have difficulty with recognizing that death is near, especially in non-cancer patients[19,20] and that palliation is often not the main treatment aim in the last phase of life, especially in patients with other diagnoses than cancer.[21] There are tools like the ‘surprise’ question (ie. the physician asks himself “Would I be surprised if this patient died in the next year?”)[22] or the RADPAC[23], that might be helpful in identifying patients that are in need of palliative care timely. Another improvement might lie in the strengthening of cooperation between GPs and district nurses. This might strengthen the influence home care can have on for instance hospitalisation. In the Netherlands, the implementation of PaTz-groups in which GPs and district nurses in a neighborhood regularly come together and systematically discuss patients with a limited life expectancy can be helpful.[24] A UK study revealed that such an approach could increase home deaths. [25] Finally, the limited use of palliative care consultants we found, and that was also found in other studies[26], might not only be a sign of GPs providing good care. It can also be an indication that the specialist palliative care structure needs further strengthening in the Netherlands. As Quill and Abernethy[11] argue, next to generalists providing basic palliative care, there is also a need for specialist palliative care for more complex problems.

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Chapter 8

General discussion

Discussion

This thesis addresses two important topics: the reasons for hospitalisations at the end of life and their avoidability. Firstly, the results from Chapters 2 to 7 will be combined with reference to the two main topics. After that, some reflections will be presented based on the results. Finally, recommendations for practice, education, research and policy will be provided.

Reasons for hospitalisations at the end of life

In the GP questionnaire study, GPs were asked about their most recent deceased patient who died non-suddenly. For patients residing at home, the most common symptomatic reasons for the final hospitalisation in the last three months of life were respiratory symptoms, digestive symptoms and cardiovascular symptoms. For a small proportion of these patients, pain or family problems were main reasons for hospitalisation at the end of life. Comparing hospitalised cancer patients (65% of all hospitalised patients) with hospitalised non-cancer patients, this thesis showed that significantly more cancer patients had digestive symptoms as the main reason for hospitalisation. The most frequent reasons for the hospitalisation of non-cancer patients were respiratory symptoms and cardiovascular complaints (Chapter 2). Pain was the most important reason for hospitalisation for a small proportion of patients (Chapter 2); the in-depth interviews among GPs, nurses and family carers revealed that pain was anticipated and prepared for more often than other symptomatic problems such as dyspnoea or digestive problems (Chapter 6). In the chart study of the GP out-of-hours cooperatives, we showed that only a minor proportion of the palliative care patients for whom the GP out-of-hours cooperative was called were referred to the hospital. The most frequent reasons for hospital referral by the GP out-of-hours cooperatives were digestive, endocrine, metabolic and nutritional and respiratory problems (Chapter 3).

Family problems were mentioned for small proportion of the patients as the main reason for the hospitalisation, in the questionnaire study among GPs and in the chart study of the GP out-of-hours cooperatives (Chapters 2 and 3). No significant evidence was found that the patients of family carers experiencing a heavy burden, as assessed by GPs, were more often hospitalised in the final week of life (Chapter 4). In interpreting these results, it should be taken into account that GPs generally assessed the burden on the family to be higher than the family carers themselves did (Chapter 4). However, in the in-depth interviews with GPs, nurses and family carers, they said that family burden is sometimes one element in the complexity of a patient's situation that can lead to hospitalisation (Chapter 6).

Finally it is important to mention some characteristics of hospitalisation. In the GP questionnaire, it was found that an acute episode played a role in two-thirds of hospitalisations, a diagnostic reason played a role in nearly half of hospitalisations and the patient's own GP initiated the hospitalisation in half of the patient cases (Chapter 2). In comparison with cancer patients, significantly more non-cancer patients had a stay of more than two days in hospital (67% versus 85% of non-cancer patients). The charts study showed that significantly fewer patients living in a home for the elderly were referred to hospital than patients living at home (Chapter 3). One third of hospitalised patients were 80 years or older. One fifth of patients received only pharmacological treatment, excluding chemotherapy, or no treatment at all in the hospital (Chapter 2).

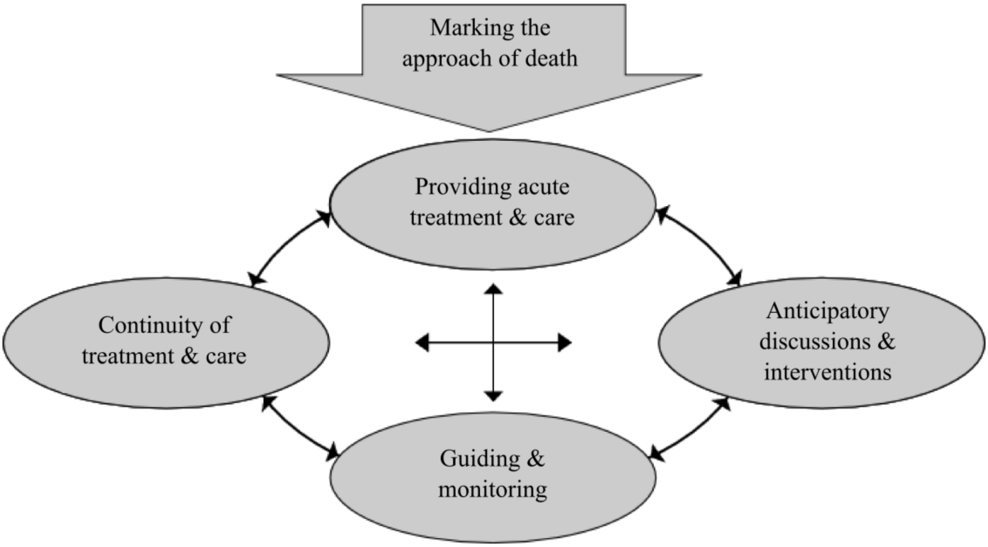
Avoidability of hospitalisations at the end of life

A quarter of all hospitalisations could have been avoided, according to GPs in the GP questionnaire study with 317 cases of hospitalised patients (Chapter 5). In the in-depth interviews with GPs, nurses and family carers, we found five interrelated strategies for avoiding hospitalisations at the end of life. These five strategies were:

1. Marking the approach of death, and shifting the mindset;
2. Being able to provide acute treatment and care at home;
3. Anticipatory discussions and interventions to deal with expected severe problems;
4. Guiding and monitoring the patient and family in a holistic way through the illness trajectory;
5. Continuity of treatment and care at home.

These five strategies needed to be provided in an interrelated way in order to avoid hospitalisations at the end of life. Therefore they are depicted in a circle as an ongoing process in the care for the patient from the moment when it was marked that there was no longer an effective treatment option available in the hospital and that the patient's life expectancy was limited, continuing until the end of life (Figure 1). For these five strategies, GPs have to work as a team with nurses and both have to have intensive contacts with the patient and their family. The five strategies are clarified in more detail below, with the findings from the in-depth interviews being combined with the quantitative results from the GP and family carer questionnaires.

Figure 1. Five interrelated strategies for avoiding hospitalisations at the end of life, from the perspectives of GPs, nurses and family carers



1. Marking the approach of death, and shifting the mindset

One third of avoidable hospitalisations could have been avoided by early discussion about the limited prognosis and/or by the medical specialist informing the patient that the illness was incurable, according to GPs in the GP questionnaire study (Chapter 5). In the in-depth interview study, we labelled this “Marking the approach of death, and shifting the mindset”. In the interviews, GPs, nurses and family of patients mentioned that to avoid hospitalisation, physicians had to have concluded and clearly communicated that the patient had a short life expectancy. This could lead to a huge shift in the mindset of patients, family carers and professionals, which often needed some time to become full awareness. This mindset shift put a different perspective on treatment in hospital, and the benefits and burden of treatment in hospital were then weighed up in a different way. GPs and nurses said that this shift in mindset did not always take place and then they were confronted with patients or family who were not ready to accept that the end was approaching. Not accepting that death was approaching could sometimes result in them "demanding" an intervention by the GP even when death was near, and this often resulted in an acute hospitalisation (Chapter 6). Also in analysing elements of palliative care associated with hospitalisations, it was found that if GPs had recognised that death was near one or more months before death, patients were less likely to be hospitalised in the last month of life (Chapter 7). However, GPs in the in-depth interview study talked about the complexity of the patient's situation, which included the difficulty to identify that death approaches, the complex disease trajectory, the psychosocial circumstances and the communication between professionals and then then hospitalisations seemed less avoidable (Chapters 4, 5 and 6).

2. Being able to provide acute treatment and care at home

Three-quarters of hospitalised patients experienced an acute situation before hospitalisation, it was found in the GP questionnaire study (Chapter 5). GPs reported that significantly more hospitalised patients experiencing an acute situation had respiratory symptoms or cardiovascular symptoms as the most important reason for hospitalisation, compared with hospitalised patients in non-acute situations (Chapter 2). GPs, nurses and family carers explained in the in-depth interview study that it is necessary to be prepared for these acute situations and also provide accurate treatment and care when the acute situation arises. When an acute situation did arise, it was found important to stay calm and sit down and discuss carefully all possible options for treatment at home or in the hospital (Chapter 6). Anticipating acute situations is discussed in the next paragraph.

3. Anticipatory discussions and interventions to deal with expected severe problems

Early discussion about withholding treatment in the hospital was mentioned in the GP questionnaire study as a strategy that could have avoided hospitalisation in half of all avoidable hospitalisations (Chapter 5). Anticipatory discussions about what to do in the case of pain, euthanasia or palliative sedation were often mentioned in the in-depth interviews with GPs (Chapter 6). GPs and nurses said in the interviews that whether or not to hospitalise was not always discussed directly, but it was touched on indirectly as the preference of patients and their family for staying at home was discussed (Chapter 6). Although only a minority of GPs mentioned in the questionnaire study that hospitalisation could have been avoided if there had been clear information transfer to the GP cooperative (Chapter 5), in the chart review of the GP out-of-hours cooperatives and in the

GP questionnaire study it was found that patients whose information was transferred to the GP out-of-hours cooperatives were significantly less often referred to hospital (Chapter 3 and 7). In addition to this, some of the GPs stated in the questionnaire that hospitalisation could have been avoided by providing “if needed” medication (Chapter 5). In the interviews, GPs and nurses said that they often anticipated severe acute problems such as pain or bleeding, explaining what patients and their family could do in such a situation. Anticipating other symptoms, such as dyspnoea or digestive problems, that may accumulate or exacerbate in the illness trajectory was less common. GPs and nurses said in the interviews that sometimes it was not possible to take anticipatory measures in the case of diseases that were progressing faster than expected or in patients with slow deterioration in whom acute exacerbations came unexpectedly (Chapter 6).

4. Guiding and monitoring the patient and family in a holistic way through the illness trajectory

In the interviews, GPs, nurses and family carers talked about the importance of guiding and monitoring the patient though the illness trajectory because often unexpected problems could arise in the illness trajectory and if these problems were recognised early and there was adequate relief then a hospitalisation could be avoided (Chapter 6). It was found that if GPs visited the patient three or more times a month in the second or third month before the patient’s death, the patient was less likely to be hospitalised (OR 2.55 CI 1.2-5.4) in the last week of life (Chapter 7). Several professionals talked about the importance of working in a team and starting palliative care early in the illness trajectory after it had been marked by professionals that death was approaching (Chapter 6). However, some GPs and also some family carers did not know about the supportive competences of nurses or that supportive nursing care could start early in the illness trajectory (Chapter 6). The chart study of the GP out-of-hours cooperatives showed that patients who received nursing care were referred to hospital significantly less often than patients who didn’t receive nursing care (Chapter 3). In the in-depth interviews, GPs and nurses said that some patients or family carers did not accept nursing care because they wanted to care for the patient till the end of life (Chapter 6). Some family carers mentioned in the interviews that they found it rewarding to care for the patient; giving good care was the final contribution they could make (Chapter 4). For several GPs and nurses, guiding and monitoring meant directing the patient and the immediate family through the illness trajectory and explain step by step what was happening in the illness trajectory (Chapter 6). It was not only the patient who needed to be monitored; the burden of family carers had to be monitored too, because many carers experienced a heavy burden, especially a high emotional burden, as was found in the GP and family carer questionnaires. Although a high proportion of family carers noted in the family carer questionnaire that they experienced a heavy burden, only a fifth of them perceived the burden as a problem. No significant relationship was found between hospitalisation in the final week of the patient's life and the heavy burden of the family caregivers, as assessed by GPs. In addition to this, in interviews family carers said that when a patient was hospitalised other burdens arose, such as a feeling that the professionals in the hospital needed to be closely supervised because of the inattentiveness of some professionals (Chapter 4).

5. Continuity of treatment and care at home

Of all the avoidable hospitalisations, one third could have been avoided by more communication between GP and medical specialist around hospitalisation and one quarter by additional care and treatment at home, according to GPs in the GP questionnaire study (Chapter 5). The patients' cases in the GP questionnaire showed that two-fifths of hospitalised patients received pharmaceutical treatment only or no treatment in the hospital. Only a small minority of patients received surgical treatment. Other patients received non-pharmaceutical treatments, such as infusion therapy, blood transfusion, tube feeding, radiotherapy, urinary catheterisation, ascites puncture, stent implementation, pleural puncture or gastric drainage. One third of all hospitalised patients stayed longer than one week in the hospital (Chapter 2). In the interviews, GPs and nurses said that many of these treatments could often be provided at home. But sometimes the patients or family carers wanted an extra confirmation in the hospital that no cure could be found and then they could accept that death was near. Also some GPs said in the interviews that when patients needed a short treatment in the hospital, it was necessary to stay in dialogue with the medical specialist and discuss when to stop this treatment in the hospital, or go on with this treatment at home in order to prevent long hospitalisations (Chapter 6).

Reflections on the reasons for hospitalisation

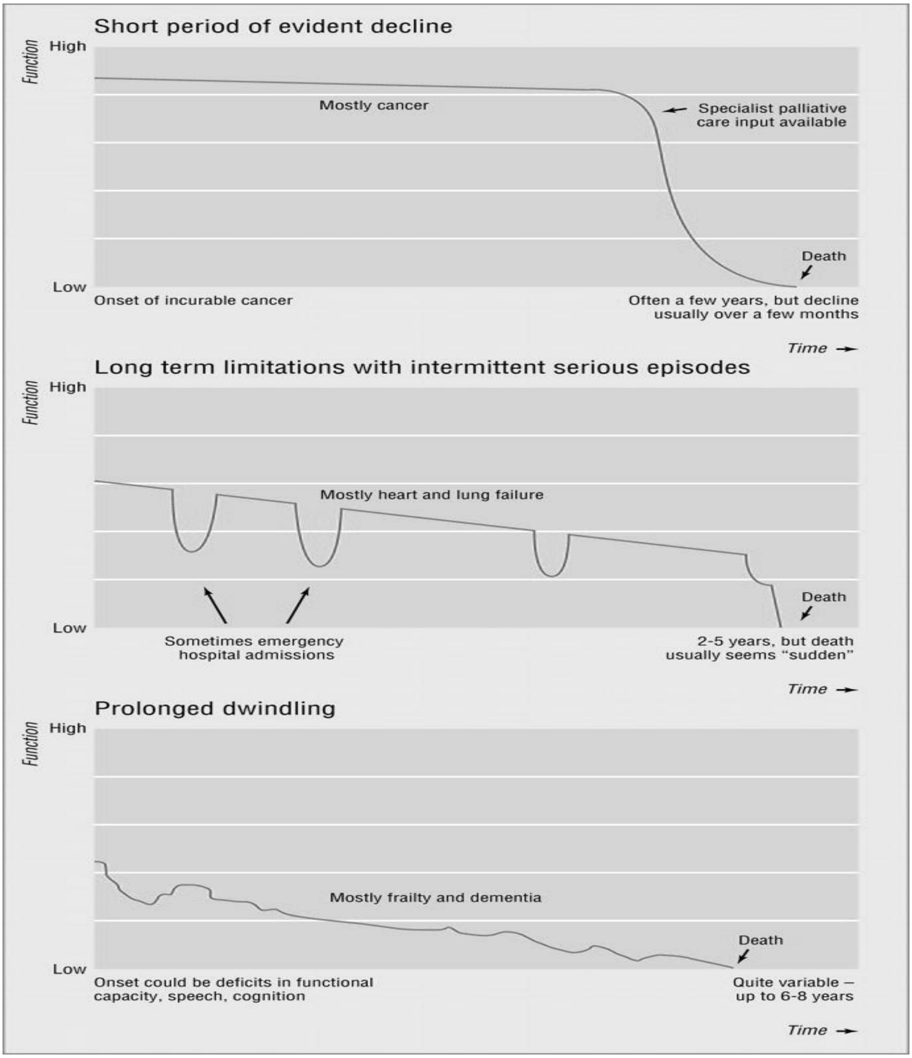
Reasons for hospitalisation related to symptoms

This thesis reported that respiratory, digestive and cardiovascular symptoms were the most important reasons for hospitalisation. Pain was mentioned as most important reason for hospitalisation for a small minority of cancer and non-cancer patients. In contrast, a review study found that in general pain was more prevalent in cancer patients in the last weeks of life than respiratory, digestive and cardiovascular symptoms.[1] A possible explanation for the fact that pain was seldom the most important reason for hospitalisation while it is more prevalent in cancer patients than other symptoms, can be found in the in-depth interview study, which showed that pain was more often anticipated by GPs than other symptomatic problems (Chapter 6). This suggests that GPs may be better in anticipating and treating pain in palliative care patients than other symptoms. Difficulties in the treatment of respiratory problems are also confirmed in other studies and whereas strong evidence-based studies are available for pain, the evidence for the treatment of dyspnoea is based on small samples.[2-4]

Illness trajectories and hospitalisations

In Chapter 2, we compared the reasons for and characteristics of the hospitalisation of cancer patients with that of non-cancer patients. This comparison enabled us to relate our results to the different illness trajectories as depicted by Lynn *et al.*[5;6] (Fig. 2). Firstly, they described a common cancer end-of-life trajectory characterised by a period of relatively good functioning with a rapid and reasonably predictable decline in clinical status and a foreseen death. Secondly, they distinguished two trajectories for non-cancer patients: a trajectory for patients with organ failure such as COPD and heart failure, and a trajectory for frail patients, such as dementia patients. Both illness trajectories are characterised by a slow functional decline, which may end in an acute event. The acute event for patients with an organ disease often concerns an acute exacerbation. For frail patients, the acute event often concerns pneumonia. This thesis showed that there was often an acute situation that resulted in hospitalisation. In the illness trajectories, we see for cancer patients that there is a decline at the end of life that can also be an acute situation and which often indicates that death is approaching. Because of this signs, it is understandable that although many cancer patients are hospitalised, they spend less time in hospital and less often die in hospital than non-cancer patients. However, many exacerbations can occur in non-cancer patients, especially in patients with heart or lung failure, as we see in the figure of the illness trajectories (Fig. 2). For this non- cancer group, we may recognise the exacerbations in the cardiovascular or respiratory problems that often led to hospitalisation. For them it is unknown whether the exacerbation is the final one before death or an exacerbation that can be treated in hospital. When it is unknown whether the exacerbations of non-cancer patients will be the last one or could be treated successfully, it is understandable that these non-cancer patients stay in hospital longer and are also more often die in hospital than cancer patients.

Figure 2 Illness trajectories at the end of life [6]



Reflections on the avoidability of hospitalisations

Number of avoidable hospitalisations

An interesting finding of the questionnaire study is that about a quarter of GPs assessed afterwards that hospitalisation could have been avoided. Whereas these Dutch GPs could have assessed this avoidability based on their long-term relationship with the patient and the family and therefore also their full knowledge of the patient’s physical and psycho-social health and the family’s capabilities, this proportion of around a quarter of avoidable hospitalisations was also found by experts in the US who assessed avoidability based on the diagnostic codes in the patients’ records.[7] In a British study, a lower proportion of 7% of hospitalisations of palliative care patients in the hospital was identified as potentially avoidable.[8] In another study of hospitalised patients, 33% were assessed as being in the last year of life,[9] which is a longer period than the three months before death that is applied in this thesis. However the above studies are based on subjective assessments and our qualitative in-depth interviews showed that palliative care at home in the last months of life is very complex. The complexity of patients’ situation included the disease trajectory, the somatic and/or psychosocial problems and the interaction between professionals and the patient. Therefore, it can be debated whether all potentially avoidable hospitalisations can be avoided in practice. Nevertheless, the potential avoidability of a quarter of avoidable hospitalisations at the end of life, as found in this thesis, is a substantial proportion for professionals to work on. The strategies presented here for avoiding hospitalisations suggest a course to be taken in order to reduce the number of hospitalisations at the end of life.

How to avoid hospitalisations?

In this thesis, an interrelated model is presented for strategies for avoiding hospitalisations from the perspective of GPs nurses and family carers (Fig. 1). The starting element is that it is necessary to mark that death approaches and to communicate that there are no effective curative treatment options. This thesis also showed that early recognition that death is near is associated with no hospitalisation in the last month of life. Marking that death is approaching is also mentioned in the Dutch palliative care module.[10] This multidisciplinary module is meant as a toolkit to improve palliative care. In this module it is explained that marking that death is approaching has consequences for weighing up the burden and benefits of treatment in hospital. For professionals, one step in marking that death approaches is identifying by asking yourself the ‘surprise’ question “Would you be surprised if this patient died in the next year?”, which is part of the internationally renowned Gold Standards Framework (GSF)[11]. The GSF and the Radboud indicators for palliative care needs (RADPAC) also provide clinical indicators for physicians to mark that the patient is in a situation in which the end is approaching.[11;12] However, as is suggested in this thesis and also shown in other studies, it is often difficult to recognise that death is approaching, especially for non-cancer patients.[13]

Another element in the interrelated model that has been presented is the anticipatory discussions and interventions to avoid hospitalisations. One form of anticipatory discussions is advance care planning, which includes discussions about medical decisions at the end of life. Other studies have indeed shown that if discussions are held about medical decisions, this results in fewer hospital deaths.[14;15] Another aspect of this strategy includes the anticipatory interventions. Other studies also show that anticipatory interventions such as the availability of “as needed” medication[16] or information transfer to the out-of-hours GP cooperative[17] can be successful in reducing hospitalisations at the end of life.

The end-of-life care pathway of the Royal College of General Practitioners and the Royal College of Nursing includes several elements of palliative care which are comparable with the strategies as presented in this study, such as identifying that the end of life approaches, discussions as the end of life approached, assessment, care planning and review, coordination of care.[18] In addition to this, our elements can also be recognised in multidimensional interventions provided by multi-disciplinary teams,[19;20] which have been shown to reduce hospitalisations at the end of life. These interventions consisted of timely discussion with the patient/family about their preferences and what might happen at the end of life, and proactive monitoring.

Professional palliative care at home

The chart study of the GP out-of-hours cooperatives showed that receiving nursing care had a significant positive association with no hospitalisation (Chapter 3), but surprisingly, this positive relationship for night care and specialised home care was not confirmed in the GP questionnaire study (Chapter 7). Night care and specialised home care are often provided in complex situations at home and it is understandable that not every complex patient can stay at home. However, a meta-analysis of studies in Western countries showed that patients who received palliative care at home from a multi-disciplinary team with highly trained nurses more often died at home compared with those who received standard care.[21] These multi-disciplinary teams for palliative care show the importance of working in a team for GPs and nurses. In the Netherlands new projects started for palliative care at home (PaTz), in which GPs reinvented the cooperation with community nurses while before some GPs didn't know about possibilities of early supportive nursing care.[22] Nurses and GPs also talked in the in-depth study about the importance of a team approach (Chapter 6).

One might question whether the approach of having specialists in palliative care provide palliative care at home (as explained in the introduction) could be a better approach than having generalists such as GPs and community nurses provide palliative care, which is the common approach in the Netherlands. However, the Netherlands has a high percentage of home deaths compared with other Western countries. In addition to this, it is suggested that specialist palliative services reach only a small proportion of patients at the end of life and therefore it is recommended that non-specialist professionals provide palliative care as well, even in countries with a highly developed system with specialist palliative care services, in order to reach more patients.[23] This thesis gives no evidence for a need to change the system of generalist GPs and nurses who provide palliative care at home but this thesis and international studies do point out that GPs and nurses need to work together as a team. However, extra training is needed to help professionals pay attention to the most common symptoms and the interrelated strategies for avoiding hospitalisations as depicted in the model (Fig. 1).

Are hospitalisations at the end of life a form of overtreatment?

In around 2012, a national debate started about the harm of prolonging life as a consequence of overtreatment. The statement of the Dutch Cancer Society with a slogan "Surrender is not an option" was questioned in a congress of the Royal Dutch Medical Association (KNMG). Following this, a national committee for customised care in the last phase of life (*Passende zorg in de laatste levensfase*) was set up in 2013. This thesis may shed some light on this debate about overtreatment at the end of life and therefore a discussion follows of 1) hospitalisation in the last three months of life, 2) the duration of hospitalisation and 3) treatment in hospital.

First, because most patients prefer to stay and to be cared for at home in the last months of life, it can be argued that hospitalisation in the last three months of life can sometimes be in itself a form of overtreatment, especially when treatment at home was a good option and when this hospitalisation could have been avoided according to the GP. Second, staying too long in hospital might also be a form of overtreatment, especially when patients have not many days to live. This thesis showed that a proportion of 40% of all final hospitalisations had a duration of a week or longer. Also, another study confirmed that not only some hospitalisations can be avoided but also the length of stay in hospital in the last month of life can be shortened.[24] Third, we showed that two-fifths of hospitalised patients received only a pharmacological intervention, excluding chemotherapy. For them it can be questioned if the hospitalisation was necessary because pharmaceutical treatment can also be offered at home. Also in another study of patients with advanced cancer, it was found that the majority received interventions such as hydration, antibiotics and oxygen therapy, which could also be administered in primary health care.[25] This suggests that for the patients who received pharmaceutical treatment only (excluding chemotherapy), hospitalisation can be seen as a form of overtreatment. However, more precise information is needed on the type of treatment in the hospital because not all GPs are well informed about the treatment in the hospital.

On the other hand it is also important to consider when hospitalisation is justified. In this thesis, the GP questionnaire study showed that GPs assessed that hospitalisation could not have been avoided in three-quarters of the patient cases they presented. The complexity of patients' cases at the end of life reveals that the illness trajectory is not always as predictable as in the schematic graphs of illness trajectories (Fig. 2).[5;6] Sometimes the illness trajectory is shorter or longer than expected. Even in situations where the physician had discussed with the patient that no effective curative treatment was available in the hospital, the patient or family can still think that "something" could be done in the hospital in the case of acute problems (Chapter 6). In another study dealing with the justification of hospitalisation at the end of life, it is also discussed that sometimes anxiety or false hope cannot be taken away and then the patient can prefer to be hospitalised.[26] In addition to this, it should also be taken into account that home is not the preferred place to die for 17% of Dutch people.[27] But even then there remains a gap between the proportion of 17% of people for whom hospital is the preferred place of death and 34% of hospital deaths in the Netherlands. It is important to bridge this gap not only from the perspective of patients' preferences but also from the perspective of the high healthcare expenditure, now and in the future.

Whereas in 2012 around 140,000 people died in the Netherlands, it is predicted that in 2030 the number of deaths will be around 180,000.[28] Knowing that around

57% of patients who died of chronic diseases may be in need of palliative care,[29] this means that the number of patients needing palliative care will increase from around 80,000 in 2012 to 100,000 patients in 2030. A Dutch study showed that of all patients who died of chronic diseases and had a non-sudden death, 55% were hospitalised.[30] This thesis reports that hospitalisation could have been avoided for around a quarter of all hospitalised patients who died non-suddenly, according to GPs (Chapter 4). When we take that proportion of hospitalisations and that proportion of avoidable hospitalisations, we estimate that in 2012 there were around 10,000 avoidable hospitalisations at the end of life and this number can grow to around 13,000 avoidable hospitalisations in 2030. Other studies confirm that good palliative care at home can reduce hospital admissions and, as a consequence of this, reduce hospital costs.[31;21;32]

Reflections on the methods

A strength of the thesis is that we used a mixed-methods study design.[33,34] Mixed-methods studies are generally very valuable in palliative care research where the majority of processes are complex. Insights gained from quantitative and qualitative approaches can complement each other to “investigate different aspects or dimensions of the same phenomena to deepen or broaden the interpretations” and understanding.[34;35] In this thesis research, the mixed-methods study design was conducted in a sequential way (Chapters 4 and 5).
Firstly, a quantitative nationwide retrospective cross-sectional questionnaire study was performed in which we asked the GPs for a real patient case of a recently deceased patient who died non-suddenly. Secondly, 30 patient cases were selected from the patient cases in the GP questionnaires, and the GPs, nurses and family carers involved were interviewed (if they were willing to participate in the interviews). We explored one of the reasons for hospitalisation - the family carers’ burden - using quantitative and qualitative approaches (Chapter 4). We also used both quantitative and qualitative approaches to explore the strategies for avoiding hospitalisation (Chapter 5). The quantitative part of the mixed-methods study let us quantify the reasons for hospitalisation and strategies for avoiding hospitalisation at the end of life. Complementing these numbers, broader insight was provided by the qualitative about what happened beyond the numbers, such as why the burden for family carers was not always perceived as a problem and the barriers GPs had to overcome to avoid hospitalisations. The combination of quantitative and qualitative research approaches provided comprehensiveness and a better

understanding of family burden as a reason for hospitalisation and the avoidability of hospitalisations at the end of life.

The quantitative questionnaire study and the qualitative in-depth studies were not only used together in a mixed-methods study design, they were also used separately. Firstly, the GP questionnaires were very useful in enabling a comparison of the groups of cancer and non-cancer patients (Chapter 2) and a comparison of patients hospitalised in the last week of life with patients who were not hospitalised in the last week of life (Chapter 7). For example, cancer patients were significantly younger, a higher proportion had digestive symptoms as reasons for hospitalisation and a lower proportion died in hospital compared with non-cancer patients (Chapter 2). In addition to this, it was found for example that information was significantly less often transferred to GP out-of-hours cooperatives compared with patients not hospitalised in the last week of life (Chapter 7). The significant differences found between groups provide valuable insights for professionals that can help them prepare for the specific problems of patients in the different patient groups and with different hospitalisation patterns at the end of life. Secondly, while in the mixed-methods study the in-depth interviews provided complimentary answers to the quantitative data from the questionnaire study, the answers to the questionnaires were set aside in the separate analyses of the in-depth interview study among GPs, nurses and family carers (Chapter 6). In this study new additional themes emerged from the interviews, which are depicted in a model (Fig.1).

The intention of our study was to look at the three perspectives of GPs, nurses and family carers in both quantitative and qualitative studies. Therefore, in the GP questionnaire the GP was also asked for the name of the home care organisation, if a nurse was involved. Then the nurse was contacted to fill in a questionnaire. We also asked the GPs to send a letter to the patient's main family carer inviting this carer to participate in the research. When the GP questionnaires, included the family carers' letter, were first sent, the response rate was very low. In reaction to this, we shortened the questionnaire and we no longer asked the GPs to send the letter to the family carer or give information about the nurse involved. Therefore in this thesis less attention is given to the nurses and family carers than was initially intended. The GPs' and family carers' questionnaires and the in-depth interviews with the family carers were used in the study of the family carers' burden (Chapter 4). For the qualitative study with the in-depth interviews, the three perspectives of GPs, nurses and family carers were valuable and they confirmed that not only GPs but also nurses and family carers have an important role in helping patients to stay at home at the end of life.

Recommendations for practice, training, research and policy

Recommendations for practice and training

This thesis showed the complexity of patients' situation and their diseases at the end of life. The complexity can be found in symptoms, which can be acute, or the illness trajectory, which can be shorter or longer than expected. Also, it is difficult for GPs, nurses, patients or family to recognise that the end approaches or to talk about the end of life when patients and/or family choose not to acknowledge that the end of life is approaching. Therefore it is recommended that customised treatment and care should be provided for palliative care patients and that patient preferences should be discussed at an early stage. Good customised palliative care needs well-educated professionals. As the WHO recently recommended[36] palliative care education is needed at three levels; 1) basic palliative care training for all health professionals; 2) intermediate training for those routinely working with patients with life-threatening illnesses; 3) specialist palliative care training to manage patients with more than routine symptom needs. For primary care this means that physicians, GPs and nurses need to be educated in palliative care in their vocational and intermediate training. In addition, specialised training in palliative care is available for GPs in the Netherlands and around 120 GPs have taken this training programme.[37] For the estimated number of 80,000 patients per year who may have a need for palliative care, this number of 120 specialists GPs in palliative care seems to be too small. If specialised GPs train their colleagues in patient case conferences about palliative care, this has been shown to be effective in reducing hospitalisations at the end of life.[38] In line with the GP specialists for palliative care, the development of specialists in nursing is also needed so that they can be part of a multidisciplinary consultation team who advise generalist professionals. To summarise the content of this vocational, intermediate and specialised training for GPs and nurses, the following elements should be included as suggested in this thesis: a) recognising that death approaches; b) communication and documentation relating to the approaching death, patient preferences and the most common problems to be expected; c) anticipating, monitoring and guiding patients with regard to the problems that can be expected, such as exacerbation and/or cumulating symptoms or family carers' burden; d) accurate acute and continuous treatment of the most common symptoms, such as dyspnoea, digestive problems, cardiovascular problems and pain, as well as tailored nursing care at home.

One of the strategies for avoiding hospitalisation was identifying that the patient had an incurable illness and acknowledging that death was approaching. In the Netherlands, there is a successful project for palliative care at home (*verbeterproject PaTz*) in which GPs and nurses have meetings and discuss for which patients it can be expected that they will die within a year. These meetings can be seen as a moment for marking that death is approaching. Then the patients who have been identified in this way are registered as palliative care patients and from this moment GPs and nurses can start with advance care planning.[39] This approach is derived from the British Gold Standards Framework.[11] It is recommended that this successful approach should be implemented and disseminated among all Dutch GPs and that they intensify their teamwork with community nurses from that marking moment. A brochure produced by the Royal Dutch Medical Association (KNMG) is also available for the early discussion of end-of-life issues for GPs, patients and their family (*Tijdig spreken over het levenseinde*) and it is recommended that this brochure should be implemented and disseminated.[40] This brochure explains that the treatment options in the event of pain can be discussed, as well as what is needed if a patient wants to die at home. It is recommended to explain in this brochure the specific illness trajectories to be expected, in which acute episodes can occur. Furthermore, it is recommended that this brochure includes a more extensive description of talking about most common ‘what if’ scenarios in the case of hospitalisation. For instance, ‘what if’ scenarios in the case of dyspnoea, digestive problems or cardiovascular problems need more explanation for patients and their family.

As we found that on the one hand it is very important that the preference for no hospitalisation is discussed but on the other hand that the patient’s own GP was not involved in half of the hospitalisations, this preference must be documented. In the Netherlands, a living will for euthanasia and ‘do not resuscitate’ orders are well known among the general public, and hospitals often use limitation of medical treatment forms or code status documentation.[41] However, it is recommended also to discuss limitation of medical treatment forms, including ‘do not hospitalise’ orders, in the primary care setting and note this in the chart for the GP out-of-hours cooperative and in the file for the nurses.

Recommendations for research

Respiratory symptoms were the most import reasons for hospitalisations among patients in general and digestive symptoms were the most important reasons for cancer patients. In the last 15 years, a lot of attention has been given to the proper treatment of pain. It is recommended that research should focus more on respiratory problems in all patients approaching the end of life and digestive symptoms in cancer patients at the end of life and how to provide tailored treatment of these symptoms at home. In addition, this thesis mainly focused on the GP perspective and it would be interesting to explore in more depth how nurses and family carers contribute in helping patients to remain at home up to the end of life. Finally, as we found, two-fifths of the hospitalisations had a duration of a week of longer. Given that spending the last days of life with family at home is important for many patients and also reduces cost, research is recommended on how to shorten the length of stay of the final hospitalisation.

This thesis presented a model (Fig. 1) of five interrelated strategies for GPs and nurses who work in a team that can help them avoid hospitalisations at the end of life. The five strategies are: 1) Marking the approach of death, and shifting the mindset; 2) being able to provide acute treatment and care at home; 3) anticipatory discussions and interventions to deal with expected severe problems; 4) guiding and monitoring the patient and family in a holistic way though the illness trajectory; 5) continuous treatment and care at home. These strategies are in line with strategies of multidisciplinary teams that have been shown to reduce the number of hospital deaths.[19;21] To find more causal evidence that this interrelated model can indeed reduce hospitalisations at the end of life, it is recommended to test this using an experimental research design such as a clinical trial.

In the model (Fig. 1), it is explained that it is important to mark that death approaches. But our study also showed how difficult it is to recognise that death is approaching, especially in non-cancer patients. Therefore research is recommended on how to recognise that death is approaching in non-cancer patients. Also for very old patients, it is important to know when to hold timely talks about end-of-life issues such as the preference for staying at home and which treatments in hospital would not be preferred. On this subject, some ideas arose from the interviews, such as talking about end-of-life issues with all frail patients, all patients aged 80 and older, or when nursing care at home starts. These suggestions need to be elaborated in explorative research.

Recommendations for policy

A major transition in long-term care, the Act long-term care,[42] is currently being prepared by the Dutch government. This transition means, amongst other things, that from 2015 only people with long-lasting, complex care needs can be admitted to a home for the elderly or a nursing home. The aim of the transition in long-term care is to enable people to live independently and retain control of their lives as long as possible, and to curb the increasing costs of health care. A study in 2006 showed that about 11% of the Dutch patients with cancer or another chronic illness as the cause of death died in a home for the elderly, 25% in a nursing home and 31% at home.[29] One of the expected consequences of the planned transition in Dutch long-term care will be that more elderly people will die at home and will not have access to round-the-clock nursing care. A consequence of no round-the-clock nursing care for elderly people at the end of life may be that the situation at home becomes too complex, resulting in hospitalisations. The policy to let elderly care-dependant people remain as long as possible in their own home in combination with the enormous growth in the number of elderly in the next few decades will also result in an increase in the demand for palliative care at home. For GPs and community nurses, the greater number of elderly people staying at home until the end of life means that they will be caring for increasing numbers of patients in need of palliative care at home. Therefore, it is important for GPs, community nurses and other relevant professionals, and also for policy makers and healthcare insurers, to be prepared for an increasing need for palliative care at home.

As discussed in this thesis, palliative care at home needs a team approach with GPs *and* nurses. In connection with the transition in long-term care[42], changes in the insurance system and the funding of long-term care at home are described in a new law which will be started in 2015. At present, nursing care at home can be provided by community nurses or certified nurse assistants. Community nurses have the main responsibility for providing the patient and their family with advice, instruction and information. Supportive nursing care early in the illness trajectory is currently often limited to, on average, five hours in the total illness process.[43] Currently, nursing care at home and support for patients and family carers is covered by a national insurance scheme (the 'AWBZ'). Nursing care at home will be part of the mandatory healthcare insurance from 2015 (in Dutch: *Zorgverzekeringswet*, Zvw).[44] Then hospital care and community nursing care, excluding some nursing tasks in supportive care at home, will be covered by the same insurance scheme. This new insurance scheme will offer new opportunities to reduce the number and length of hospitalisations because one insurance scheme will cover both hospital care and nursing care at home. One opportunity is faster referral from hospital to home for patients with palliative care needs. Another opportunity of this new insurance scheme is that the highly qualified community nurses will obtain more freedom to decide how much care to provide and for which patients nursing care can be provided. For community nurses, it is recommended that they take advantage of this freedom and start supportive nursing care early in the illness trajectory, from the moment that it is marked that death is approaching, and then work together intensively with GPs. In addition to these changes for community nurses, from 2015 home help care (for cleaning the home) and support for patients and informal carers, e.g. in the sense of respite care or day care, will have to be organised by the municipal authorities (within the legal framework of the Dutch Social Support Act (*Wet maatschappelijke ondersteuning*, or Wmo).[45] The expectation is that in the future fewer people will be able to rely on these types of professional support since municipalities will have limited budgets for organising this. Therefore, it is recommended that policy makers be aware of this reduction in professional support and home help care, which may result in more hospitalisations at the end of life and therefore also increase healthcare costs.

The latest letter from the Minister of Health, Welfare and Sports about palliative care is called "Invest in palliative care".[46] In our research it was found that a quarter of hospitalisations at the end of life could have been avoided. To avoid hospitalisations, strategies were suggested for GPs and nurses, such as anticipatory discussions, guiding and monitoring. Therefore regular contact with the patient is needed. Patients who have frequent visits from their GP are less likely to be hospitalised (Chapter 7). At present, an idea is being debated in which hospital specialists are paid extra for discussing patients' preferences (*Kijk en luistergeld*). It is recommended that extra payments should also be made for the anticipatory discussions, guiding and monitoring at the end of life by GPs. To summarise all the above recommendations: extra GP visits, visits by nurses as case managers or for advice, instruction and information, investment in vocational and specialist training for GPs and nurses, and more research can improve the quality of palliative care at home and may reduce costs in health care in the last months of life. Therefore we agree that an investment in palliative care by the Minister of Health, Welfare and Sports is a good investment.

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Samenvatting

Samenvatting

De meeste mensen wensen thuis te blijven aan het einde van hun leven. Bekend is dat ruim de helft van de patiënten die niet plotseling sterven in de laatste drie levensmaanden wordt overgeplaatst van thuis naar het ziekenhuis. Ziekenhuisopname aan het levenseinde is vanuit het perspectief van de meeste patiënten vaak ongewenst, evenals vanuit het oogpunt van kwaliteit van zorg en kosten voor de gezondheidszorg. Tot 2010 was nog weinig bekend over de redenen en vermijdbaarheid van ziekenhuisopname aan het levenseinde van patiënten die thuis verbleven. Daarom was het van belang om deze twee aspecten te onderzoeken. Doel van het onderzoek was het verkennen van de redenen en vermijdbaarheid van ziekenhuisopname aan het levenseinde vanuit het perspectief van huisartsen, verpleegkundigen en mantelzorgers.

Het onderzoek bestond uit twee delen. Ten eerste is een retrospectief dossieronderzoek uitgevoerd bij alle huisartsenposten in de regio Amsterdam. Over een periode van een jaar werden alle patiënten geselecteerd die een behoefte hadden aan palliatieve zorg. Dit resulteerde in 553 casussen van patiënten, waarbij 13% van de patiënten naar het ziekenhuis was verwezen. Ten tweede werd een *mixed methods* onderzoek uitgevoerd door middel van een kwantitatief vragenlijstonderzoek en kwalitatieve diepte-interviews. Uit alle huisartsen in Nederland is een steekproef getrokken. Van alle 1.601 huisartsen die onder de inclusiecriteria vielen reageerde 37%. Er werd ze gevraagd naar hun laatste, niet-plotseling overleden patiënt. Een deel van de huisartsen is gevraagd naar een patiënt die niet in de laatste drie levensmaanden in het ziekenhuis was opgenomen (respons n=271) en een deel is gevraagd naar een patiënt die wel in het ziekenhuis was opgenomen (respons n=322). Alleen in de eerste verzending van de vragenlijst is huisartsen naar de meest betrokken mantelzorger gevraagd; 83 mantelzorgers vulden de vragenlijst in. Voor de diepte-interviews zijn op basis van patiëntkenmerken zoals die in de vragenlijst vermeld stonden 20 gehospitaliseerde en 10 niet-gehospitaliseerde patiënten uitgekozen. Dit resulteerde in 59 diepte-interviews met 26 huisartsen, 15 verpleegkundigen en 18 mantelzorgers.

In hoofdstuk twee tot en met zeven van dit proefschrift zijn de resultaten van bovenstaande onderzoeken besproken. Deze resultaten worden in deze samenvatting geclusterd aan de hand van de twee hoofdthema’s van dit proefschrift, namelijk de redenen van ziekenhuisopname aan het levenseinde en de vermijdbaarheid van ziekenhuisopname aan het levenseinde.

Deel 1 Redenen voor ziekenhuisopname aan het levenseinde

Belangrijkste redenen voor de laatste ziekenhuisopname voor overlijden waren benauwdheid, digestieve problemen of cardiovasculaire problemen. Van alle opgenomen patiënten had 65% kanker. Bij kankerpatiënten waren digestieve problemen significant vaker de belangrijkste reden voor ziekenhuisopname dan bij niet-kankerpatiënten. Benauwdheid en cardiovasculaire problemen waren bij niet-kankerpatiënten vaker de belangrijkste reden voor ziekenhuisopname (hoofdstuk 2). Voor een kleine groep patiënten was pijn of mantelzorgbelasting de belangrijkste reden voor ziekenhuisopname (hoofdstuk 2). Uit de diepte-interviews met huisartsen, verpleegkundigen en nabestaanden kwam naar voren dat er vaak geanticipeerd was op pijn, maar veel minder vaak op andere symptomen als benauwdheid en digestieve problemen (hoofdstuk 6). Dossieronderzoek bij huisartsenposten liet zien dat maar een klein deel van de patiënten met een palliatieve zorgvraag werd doorverwezen naar het ziekenhuis. De meest voorkomende redenen voor doorverwijzing vanuit de huisartsenposten waren digestieve problemen, endocriene-, metabolische- en voedingsproblemen en problemen met benauwdheid (hoofdstuk 3).

Problemen met mantelzorg was voor een klein deel van de patiënten de belangrijkste reden voor ziekenhuisopname. Dit bleek uit het vragenlijstonderzoek onder huisartsen en het dossieronderzoek bij huisartsenposten (hoofdstuk 2 en 3). In het vragenlijstonderzoek is geen bewijs gevonden dat patiënten met mantelzorgers die naar inschatting van de huisarts een zware belasting ervoeren vaker de laatste week voor overlijden in het ziekenhuis werden opgenomen (hoofdstuk 4). Echter, huisartsen, verpleegkundigen en mantelzorgers vertelden in de diepte-interviews dat de overbelasting van mantelzorgers soms een van de redenen was die meespeelde bij ziekenhuisopname (hoofdstuk 6).

Een aantal karakteristieken rondom de laatste ziekenhuisopname voor overlijden is het vermelden waard. Uit de vragenlijsten onder huisartsen kwam naar voren dat een acute situatie bij twee derde van de ziekenhuisopnames een rol speelde, dat bij bijna de helft diagnostische redenen een rol speelden en dat bij de helft van de patiëntcasussen de eigen huisarts de ziekenhuisopname initieerde (hoofdstuk 2). Niet-kankerpatiënten verbleven significant vaker langer dan twee dagen in het ziekenhuis dan kankerpatiënten: 67% versus 85% bij niet-kankerpatiënten (hoofdstuk 2). Uit het dossieronderzoek bleek dat patiënten die in verzorgingshuizen woonden aan het levenseinde significant minder vaak door de huisartsenpost naar het ziekenhuis werden doorverwezen dan patiënten die thuis woonden (hoofdstuk 3). Een derde van de gehospitaliseerde patiënten was 80 jaar of ouder. Een vijfde van de patiënten ontving geen behandeling of enkel medicamenteuze behandeling in het ziekenhuis, exclusief chemotherapie (hoofdstuk 2).

Deel 2 Vermijdbaarheid van ziekenhuisopname

Achterafgezien kon volgens huisartsen uit het vragenlijstonderzoek naar schatting een kwart van alle ziekenhuisopnames voorkomen worden (hoofdstuk 5). Gebaseerd op de interviews met huisartsen, verpleegkundigen en mantelzorgers zijn in dit proefschrift vijf met elkaar samenhangende strategieën gepresenteerd om ziekenhuisopname te voorkomen. In deze vijf strategieën zijn ook de resultaten uit het vragenlijstonderzoek met huisartsen en mantelzorgers verwerkt. De vijf strategieën zijn:

1. Markeren dat de dood nadert en een omslag in het denken maken;
2. In staat zijn om acute behandeling en zorg te geven aan het levenseinde;
3. Anticiperende gesprekken voeren en interventies plegen voor het omgaan met te verwachten problemen;
4. Begeleiden en monitoren van patiënten en familie op een holistische wijze gedurende het ziekteproces;
5. Continuïteit in zorg en behandeling thuis.

Ad 1: Markeren dat de dood nadert en een omslag in het denken maken

Een derde van de vermijdbare ziekenhuisopnames kon achteraf gezien voorkomen worden door het vroegtijdig bespreken van de beperkte levensverwachting en/of door informatie van de (medisch) specialist dat de patiënt ongeneeslijk ziek was (hoofdstuk 5). In het kwalitatieve onderzoek werd dit gelabeld als “markeren en een omslag in het denken maken dat de dood nadert”. Huisartsen en verpleegkundigen vertelden in de interviews dat het bij vermijden van ziekenhuisopname van belang was dat artsen hadden geconcludeerd dat de patiënt een beperkte levensverwachting had en dit duidelijk hadden gecommuniceerd met de patiënt en hun familieleden. Dit kon leiden tot een enorme verschuiving in het denken van patiënten, hun mantelzorgers en professionals, die soms enige tijd nodig hadden om tot het volle besef hiervan te komen. De omslag in het denken dat het levenseinde naderde bood een ander perspectief op behandeling in het ziekenhuis, waardoor de voor- en nadelen daarvan op een andere manier gewogen werden. Huisartsen en verpleegkundigen vertelden dat deze verandering in het denken bij patiënten en mantelzorgers niet altijd plaatsvond. Zij werden geconfronteerd met patiënten of mantelzorgers die er niet klaar voor waren om te accepteren dat het levenseinde nabij was. Het niet-accepteren dat de dood nabij was resulteerde soms in een dwingende vraag van patiënten en/of mantelzorgers om een interventie van de huisarts. Uiteindelijk resulteerde dit vaak in een acute ziekenhuisopname bij ernstige problemen (hoofdstuk 6). Hierbij moet worden opgemerkt dat het door de complexiteit van de situatie, bijvoorbeeld door multimorbiditeit of een onduidelijke oorzaak van de symptomen, niet altijd helder was dat de dood naderde, zoals huisartsen in de interviews aangaven. Wanneer dat niet helder was, leek ziekenhuisopname minder vermijdbaar (hoofdstuk 4 en 5).

Ad 2: In staat zijn om acute behandeling en zorg thuis te bieden
Driekwart van de opnames was acuut, bleek uit het vragenlijstonderzoek onder huisartsen (hoofdstuk 5). Bij acuut opgenomen patiënten rapporteerden huisartsen significant vaker klachten van benauwdheid of cardiovasculaire klachten dan bij niet-acuut opgenomen patiënten (hoofdstuk 2). Huisartsen, verpleegkundigen en mantelzorgers legden in de diepte-interviews uit dat het belangrijk is om te anticiperen op deze acute situaties, om vervolgens de meest accurate behandeling en zorg thuis te kunnen bieden. Bij acute situaties werd het belangrijk gevonden om kalm te blijven en met de patiënt en/of familie rond de tafel te gaan zitten om de mogelijke opties voor behandeling thuis of in het ziekenhuis zorgvuldig met hen te bespreken (hoofdstuk 6). Anticiperen op acute situaties wordt nader besproken in de volgende paragraaf.

Ad 3: Anticiperende gesprekken voeren en interventies plegen voor het omgaan met te verwachten problemen
Vroegtijdig spreken over het stoppen van behandeling in het ziekenhuis werd bij de helft van alle vermijdbare ziekenhuisopnames genoemd als strategie om ziekenhuisopname te vermijden (hoofdstuk 5). Anticiperende gespreksvoering over wat gedaan kan worden bij pijn en wat de mogelijkheden zijn bij euthanasie of palliatieve sedatie werd in de diepte-interviews vaak door huisartsen genoemd (hoofdstuk 6). Huisartsen en verpleegkundigen vertelden in de interviews dat de wens tot wel of geen ziekenhuisopname veelal niet direct met patiënten en hun familie werd besproken, maar dat wel op indirecte manier werd gesproken over de wens om aan het levenseinde thuis te blijven (hoofdstuk 6). Hoewel een klein aantal huisartsen in het vragenlijstonderzoek invulde dat ziekenhuisopname mogelijk voorkomen had kunnen worden door een duidelijke overdracht aan de huisartsenpost (hoofdstuk 5), bleek uit het dossieronderzoek bij huisartsenposten en het vragenlijstonderzoek bij huisartsen dat als er informatie was overgedragen aan de huisartsenpost, patiënten significant minder vaak in het

ziekenhuis waren opgenomen (hoofdstuk 3 en 7). Daarnaast vulden enkele huisartsen in dat ziekenhuisopname voorkomen had kunnen worden door het voorschrijven van “zo nodig” medicatie (hoofdstuk 5). In de interviews vertelden huisartsen en verpleegkundigen dat zij vaak anticipeerden op te verwachten problemen als pijn en bloedingen en hoe patiënten en hun familie in een dergelijke situatie konden handelen. Minder vaak werd geanticipeerd op andere potentiële symptomen die zich konden opstapelen of plotseling uitbreken, zoals benauwdheid of digestieve problemen. Hierbij maakten zij de kanttekening dat het soms niet mogelijk was om te anticiperen op ziekten die sneller verliepen dan verwacht, of wanneer er plotseling verergering van problemen optrad bij patiënten die langzaam achteruitgingen (hoofdstuk 6).

Ad 4: Begeleiden en monitoren van patiënten en familie op een holistische wijze gedurende het ziekteproces

In de interviews vertelden huisartsen, verpleegkundigen en mantelzorgers over het belang van begeleiden en monitoren van patiënten gedurende het ziektetraject, omdat hierin vaak onverwachte problemen rezen. Als deze problemen vroeg in het ziektetraject werden herkend en adequaat behandeld, was het mogelijk om ziekenhuisopname te voorkomen. Voor veel huisartsen en verpleegkundigen hield het begeleiden van de patiënt en de directe naasten in hen als een gids door het ziektetraject heen te leiden en stap voor stap uit te leggen wat er gebeurde (hoofdstuk 6). Het bleek dat als huisartsen de patiënt drie keer of vaker per maand bezochten in de tweede of derde maand voor overlijden, de patiënt significant minder kans had op ziekenhuisopname in de laatste week voor overlijden (hoofdstuk 7). Veel professionals vonden het belangrijk dat er in een team van huisartsen en verpleegkundigen werd gewerkt nadat was gemarkeerd dat de dood naderde (hoofdstuk 6). Uit de gesprekken kwam echter ook naar voren dat sommige huisartsen en nabestaanden niet goed op de hoogte waren van de begeleidende competenties van verpleegkundigen en van het feit dat verpleegkundigen voor advies, instructie en voorlichting (AIV) vroegtijdig in het ziektetraject ingezet konden worden (hoofdstuk 6). Uit het dossieronderzoek bleek dat als patiënten verpleegkundige zorg ontvingen, zij significant minder vaak naar het ziekenhuis werden verwezen (hoofdstuk 3). In de diepte-interviews vertelden huisartsen en verpleegkundigen dat sommige patiënten en mantelzorgers geen verpleegkundige zorg accepteerden, omdat zij zelf tot het einde toe zorg wilden verlenen (hoofdstuk 6). Sommige mantelzorgers vertelden in de interviews dat het zorgen hen veel voldoening gaf, omdat dat het laatste was wat zij konden doen (hoofdstuk 4). Het was niet alleen de patiënt die gemonitord moest worden, maar ook het monitoren van de belasting van de mantelzorgers was belangrijk. Veel mantelzorgers ervoeren een zware, met name emotionele belasting, zo bleek uit de vragenlijsten die huisartsen en mantelzorgers invulden. Hoewel een hoog percentage mantelzorgers in de vragenlijst noteerde een zware belasting te ervaren, gaf slechts een vijfde daarvan aan dat problematisch te vinden. Geen significante relatie werd gevonden tussen ziekenhuisopname in de laatste week voor overlijden van patiënten en de zware belasting van mantelzorgers zoals de huisarts die had ingeschat in de tweede en derde maand voor het overlijden. Daarnaast vertelden mantelzorgers in de interviews dat er na hospitalisatie van de patiënt een ander soort belasting ontstond, zoals het gevoel om professionals te moeten controleren vanwege hun onoplettendheid (hoofdstuk 4).

Ad 5: Continue zorg en behandeling thuis
Volgens huisartsen in de huisartsenvragenlijsten kon een kwart van alle vermijdbare ziekenhuisopnames vermeden worden door meer zorg en behandeling thuis te geven en een derde door meer communicatie tussen huisarts en specialist (hoofdstuk 5). Uit de casussen van patiënten in de huisartsenvragenlijsten kwam naar voren dat twee vijfde van de gehospitaliseerde patiënten geen, of enkel farmaceutische behandeling in het ziekenhuis ontving. Een klein percentage patiënten was in het ziekenhuis geopereerd. Andere patiënten ontvingen niet-farmacologische behandelingen, zoals behandeling met een infuus, bloedtransfusie, voedseltoediening via een sonde, radiotherapie, urinekatheterisatie, ascitespunctie, stentimplantatie, pleurapunctie of maag hevelen. Een derde van de gehospitaliseerde patiënten bleef langer dan een week in het ziekenhuis (hoofdstuk 2). In de interviews vertelden huisartsen en verpleegkundigen dat veel van deze behandelingen thuis gegeven konden worden. Een aantal huisartsen vertelde dat sommige behandelingen slechts een korte ziekenhuisopname behoefden, waarbij het dan nodig was dat de huisarts in contact bleef met de specialist om de grenzen van behandeling te bespreken, zodat de patiënt niet onnodig lang in het ziekenhuis bleef. Soms wilden patiënten en/of mantelzorgers in het ziekenhuis een extra bevestiging krijgen dat er geen behandelingsmogelijkheid meer was. Wanneer dit werd bevestigd, konden zij accepteren dat de dood nabij was (hoofdstuk 6).

Samenhang tussen de strategieën

Uit de diepte-interviews kwam naar voren dat het noodzakelijk is dat de vijf strategieën in samenhang worden toegepast om ziekenhuisopname aan het levenseinde te voorkomen (fig. 1). De strategieën treden in werking vanaf het moment dat is gemarkeerd dat effectieve behandeling in het ziekenhuis niet meer mogelijk is. In de praktijk leidde deze markering vaak tot een omslag in het denken van patiënten en familie en duurde het nog een tijdje voordat zij tot het volle besef hiervan kwamen. Vanaf het markeren dat het levenseinde nadert werden de voor- en nadelen van ziekenhuisopname gewogen op basis van de korte levensverwachting die patiënten nog hadden. Thuis verblijven, kwaliteit van leven en comfort werden dan belangrijker. Na het markeren startte voor huisartsen en verpleegkundigen het proces van anticiperen op problemen, gidsen en monitoren, alsmede het bieden van acute en continuïteit van zorg en behandeling thuis. Daarom zijn deze vier strategieën als een doorlopend proces dat geleidelijk aan begint en steeds intensiever wordt tot aan het levenseinde in een cirkel weergegeven. Echter, de situatie van patiënten is vaak complex door ziektetrajecten die soms korter of langer zijn dan verwacht of door onverwachte, ernstige en acute problemen bij patiënten en mantelzorgers. Daarnaast is er geen continue beschikbaarheid van eigen huisartsen en verpleegkundigen. Deze complexiteit van de situatie rondom de patiënt brengt met zich mee dat ziekenhuisopname soms toch de beste optie is.

Conclusie

De voornaamste redenen voor ziekenhuisopname in de laatste drie levensmaanden zijn: benauwdheid, digestieve problemen en cardiovasculaire problemen. Achteraf gezien vindt een kwart van de huisartsen dat ziekenhuisopname van de patiënt op basis waarvan de vragenlijst is ingevuld voorkomen had kunnen worden. Vijf met elkaar samenhangende strategieën om ziekenhuisopname aan het levenseinde te voorkomen zijn:

1. Markeren dat de dood nadert en een omslag in het denken maken;
2. In staat zijn om acute behandeling en zorg te geven aan het levenseinde;
3. Anticiperende gesprekken voeren en interventies plegen voor het omgaan met te verwachten problemen;
4. Begeleiden en monitoren van patiënten en familie op een holistische wijze gedurende het ziekteproces;
5. Continue zorg en behandeling thuis.

Hoewel de methode van onderzoek vooral beschrijvend was, bieden de uitkomsten (o.a. een kwart vermijdbare ziekenhuisopnames, de meest voorkomende redenen van ziekenhuisopname en vijf strategieën om ziekenhuisopname te vermijden) voldoende hefbomen voor professionals om multidisciplinaire richtlijnen te ontwikkelen om met elkaar het aantal ziekenhuisopnames aan het levenseinde te reduceren. De complexiteit van de situatie rondom de patiënt omvat vooral het onvoorspelbare ziektetraject, de veelal acute problemen van somatische of psychosociale aard en de interactie tussen professionals. Ten gevolge van deze complexiteit blijkt in de praktijk dat het moeilijk is om ziekenhuisopname aan het levenseinde te voorkomen.

Aanbevelingen

De meest voorkomende symptomatische redenen voor de laatste ziekenhuisopname voor overlijden zijn: benauwdheid, digestieve problemen en cardiovasculaire problemen. Om te voorkomen dat deze veel voorkomende symptomen leiden tot ziekenhuisopname, zullen artsen en wijkverpleegkundigen moeten anticiperen door patiënten en hun familie tijdig hierover te informeren en door patiënten en mantelzorgers gedurende het ziekteproces regelmatig te bezoeken om hen te begeleiden en te monitoren op veelvoorkomende symptomen. Deze aspecten zullen in initiële opleidingen en bijscholingen van huisartsen en verpleegkundigen aan de orde moeten komen. Ook zijn meer in palliatieve zorg gespecialiseerde huisartsen en verpleegkundigen nodig, die vervolgens hun collega's in palliatieve zorgverlening kunnen trainen. Daarnaast zal meer onderzoek naar thuisbehandeling van de veelvoorkomende symptomen gedaan moeten worden.

Voor het vermijden van ziekenhuisopnames worden in dit proefschrift vijf samenhangende strategieën gepresenteerd. Van belang is dat huisartsen en verpleegkundigen zich als een team hierop richten. Sommige initiatieven in Nederland gaan al de goede richting uit. Zo laten PaTz-groepen (Palliatieve Thuiszorg-groepen) zien dat huisartsen en wijkverpleegkundigen elkaar weer vinden. In deze PaTz-groepen markeren huisartsen en wijkverpleegkundigen samen dat bij bepaalde patiënten de dood nadert en maken een zorgplan voor het tijdig anticiperen, begeleiden, monitoren en accuraat behandelen en verzorgen van patiënten. Het is aan te bevelen dat het model zoals gepresenteerd in dit proefschrift wordt uitgewerkt als interventie in PaTz-groepen. Vervolgens kan het wetenschappelijk worden getoetst, waarbij de hypothese luidt dat het een positief effect heeft op het voorkomen van ongewenste ziekenhuisopnames aan het levenseinde.

In Nederland heerst echter ook een trend die het voorkomen van ongewenste hospitalisaties aan het levenseinde zal bemoeilijken. De voorgenomen decentralisaties in de zorg, vastgelegd in nieuwe wetten voor langdurige zorg en maatschappelijke ondersteuning, hebben als doel dat meer ouderen thuis blijven wonen in plaats van naar een verzorgingshuis te gaan. Dit heeft tot gevolg dat meer oudere mensen met complexe problemen thuis palliatieve zorg nodig zullen hebben. Waar in de verzorgingshuizen 24-uurstoezicht is, is dat thuis meestal niet mogelijk. Uit het dossieronderzoek bleek dat patiënten in verzorgingshuizen die palliatieve zorg nodig hadden significant minder vaak door de huisartsenpost naar het ziekenhuis werden doorverwezen dan patiënten die thuis woonden. De complexiteit van zorg voor ouderen thuis en het ontbreken van 24-uurszorg thuis kan tot gevolg hebben dat ouderen aan het levenseinde vaker dan nu in het ziekenhuis worden opgenomen. Daarnaast is het vaak moeilijk om bij ouderen te identificeren dat het levenseinde nadert en om een moment te vinden om dat met ze te bespreken. Naar dit markeren van het naderende levenseinde zal meer onderzoek gedaan moeten worden. Het is van belang dat ouderen hierbij betrokken worden, zodat hun wensen worden meegewogen bij het bepalen van het juiste moment om over het levenseinde te spreken.

Dankwoord

Dankwoord

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About the author

Curriculum vitae

Ria de Korte-Verhoef (1959) volgde haar opleiding tot verpleegkundige op het VUmc en startte haar loopbaan op een afdeling oncologie, als verpleegkundige in de wijk en als manager in een verpleeghuis. In 1990 rondde zij de hbo-lerarenopleiding Verpleegkunde af en werd docent voor ziekenverzorgenden, in 1996 gevolgd door voltooiing van een master Gezondheidswetenschappen, afstudeerrichting Verplegingswetenschap. Ria werd vervolgens programmasecretaris voor de landelijke commissie Centra voor Ontwikkeling van Palliatieve Zorg (COPZ), die de opdracht kreeg om onderzoek, onderwijs en structuren in de palliatieve zorg te verbeteren. Daarna werkte zij achtereenvolgens als beleidsmedewerker bij de Beroepsorganisatie voor Verpleegkundigen en Verzorgenden (V&VN) en in de programmaleiding van het landelijk patiëntveiligheidsprogramma medicatieveiligheid ‘Zorg voor Beter’. Van 1997 tot 2013 was Ria ook als docent Verplegingswetenschap verbonden aan het UMC Utrecht en doceerde zij bij Gezondheidswetenschap aan de VU te Amsterdam. Daarnaast werkte zij mee aan een onderzoek naar palliatieve zorg bij kinderen en naar vroegsignalering in de palliatieve fase door verpleegkundigen van de thuiszorg. Dit jaar hoopt Ria haar registratie tot epidemioloog te behalen. Dit PhD-onderzoek is uitgevoerd op het EMGO+ Instituut, afdeling Sociale Geneeskunde van het VUmc te Amsterdam. Sinds acht jaar is Ria ook bestuurlijk en politiek actief, o.a. als voorzitter van de Wmo-adviesraad, als CDA-bestuurslid op lokaal, provinciaal en landelijk niveau en sinds medio 2014 als CDA-gemeenteraadslid in de gemeente De Ronde Venen. Ria is getrouwd, heeft vier kinderen en woont in het mooie dorp Baambrugge.

Curriculum vitae

Ria de Korte-Verhoef (1959) trained as a nurse at the VU University Medical Center in Amsterdam. She started her career working on an oncology ward, as a community nurse and as a nursing home manager. In 1990, she completed teacher training in Nursing at a university of applied sciences and started to teach nursing auxiliaries. This was followed in 1996 by a Master's degree in Health Science, specialising in Nursing Science. Ria then became the programme secretary for the national review committee for the Centres for the Development of Palliative Care (*Centra voor Ontwikkeling van Palliatieve Zorg*, or COPZ), which had been given the task of improving research, education and organisational structures in palliative care. After this, she worked successively as a policy officer for the professional association of nurses and care workers (*Verpleegkundigen & Verzorgenden Nederland*, or V&VN) and as part of the programme management of *Zorg voor Beter*, the national programme for patient safety and safe medication. Ria also worked as a lecturer in Nursing Science at the UMC Utrecht from 1997 to 2013, and she taught Health Science at the VU University Amsterdam. In addition, she was involved in a study of palliative care for children and in developing early warnings for the palliative phase for home care nurses. Ria hopes to be registered as an epidemiologist this year. This PhD study was carried out at the EMGO Institute for Health and Care Research, Department of Public and Occupational Health, VU University Medical Center in Amsterdam. Ria has also been actively involved in public administration and politics for the past eight years. For instance, she chaired the advisory council on the Medical Research (Human Subjects) Act (*Wmo*), she has been a committee member in the Christian Democrat party (CDA) at the local, provincial and national levels, and in March 2014 she was elected for the CDA to the municipal council in the municipality of De Ronde Venen. Ria is married, has four children and lives in the lovely village of Baambrugge.

List of publications

International articles

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