

# Provision of end-of-life care in general practice

PhD dissertation

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# PROVISION OF END-OF-LIFE-CARE IN GENERAL PRACTICE

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# PREFACE

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## MOTIVATION

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When I was a newly hatched physician, I was fortunate to work on a geriatric ward. Many frail elderly people were admitted to the ward. My inspiring and experienced colleagues showed me the importance of talking about the end of life to patients and their relatives. I saw how it helped patients at the end of life and their relatives.

It made me aware of how little we talk about dying in the health care system even though dying is a universal human activity that happens daily.

When my dear grandfather passed away, I came across the TED talk “Let’s talk about dying” by Peter Saul. In this, he introduced a subtle way of raising end-of-life questions, by asking “in the event that you became too sick to speak for yourself, who would you like to speak for you?”

This simple question made me wonder once again, why we talk so little to our patients about the end of life. That is when I decided to commit myself to do research in the palliative field.

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## OUTLINE OF THE DISSERTATION

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In **chapter 1**, I introduce the research domain to which this dissertation belongs and outline the basic premises of the dissertation. The key concepts are defined. The aims of the dissertation are presented at the end of chapter 1. **Chapter 2** describes the settings, methods, and data used in the three papers. **Chapter 3** summarises the main results of the three papers. **Chapter 4** is a discussion of the methods used, their strengths and weaknesses, potential bias, and validity. **Chapter 5** is a discussion of the results of the three papers. In **Chapter 6**, overall conclusions are presented based on the three papers. **Chapter 7** brings perspectives to the results and suggests areas of future research. **Chapter 8** summarises the dissertation in English and in Danish. **Chapter 9** contains all the references.

The appendix contains the questionnaire used in study II, materials and letters of invitation used in the intervention.

This PhD dissertation is based on the following studies, which will be referred to by their Roman numerals. They are found at the end of the dissertation:

- |           |  |
|-----------|--|
| Paper I   | Home visiting propensity among general practitioners and associations with cancer patients' place of care and death                      |
| Paper II  | Danish general practitioners' self-reported competences in end-of-life care  |
| Paper III | Development, modelling, and pilot testing of a complex intervention to support end-of-life care provided by Danish general practitioners |

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## ABBREVIATIONS

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AKW	Anna Kirstine Winthereik (researcher)
CI	Confidence Interval
CiP	Cancer in General Practice (an administrative unit in Central Denmark Region)
CME	Continuing Medical Education
COPD	Chronic Obstructive Pulmonary disease
CPR number	Unique Danish personal identification number
DAK-E	The Danish Quality Unit of General Practice
DAMD	Danish database with data from general practice
DCR	The Danish Cancer Register
DST	Statistics Denmark
EDS	Electronic Decision Support
GPs	General Practitioners
HSR	The Danish National Health Service registry
MRC	Medical Research Council (UK)
NPR	The National patient registry
PL	Patient lists
SIR	Standard Incidence Rate

# **CHAPTER 1:**

## **INTRODUCTION**

*“The GP spontaneously came to visit us every day until it was over. He came and asked if there was anything that he could do. And it was an incredible relief not having to call him first... Then, I really felt that he gave me all the support a doctor could give“ [1]*

This dissertation focuses on the end of life care provided by general practitioners (GPs) to their patients in the last part of their lives.

---

## 1.1 CARE IN PALLIATIVE TRAJECTORIES

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In 2002 the World Health Organisation (WHO) defined palliative care as:

*“An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” [2].*

This definition of palliative care embraces all patients regardless of diagnosis, their relatives, and scope of needs and refers to care during the whole disease trajectory. However, there is no common understanding of palliative care despite the definition. The understanding and interpretation of palliative care vary both in clinical work and in research with regard to patient groups and time for the provision [3-5]. Terms such as palliative care, terminal care, and end-of-life care are inconsistently used to describe care provided to patients with life-threatening illness.

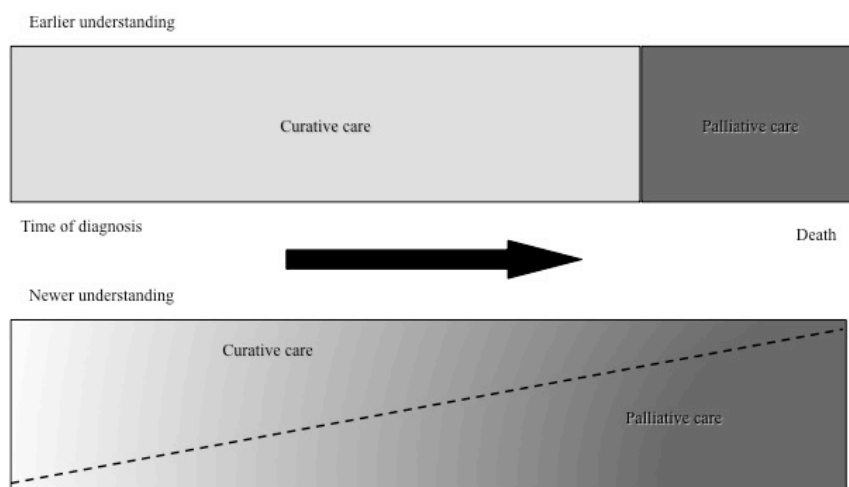
The difference in the understanding of palliative care can be depicted as in Figure 1. The top figure reflects a traditional understanding, where palliative care is initiated when the curable treatment is suspended. The bottom figure reflects the understanding of palliative care defined by the WHO, where palliative care is commenced at the time of diagnosis side by side with the curative care.

Hanratty et al. investigated the understanding of palliative care among doctors (GPs, cardiologists, geriatricians, palliative care physicians, and general physicians). They revealed that the ‘old concept’ with a clear transition between curative to palliative care was still dominant in 2006:

*“The difficulties of recognizing the right time to switch to palliative care surfaced as a major challenge” [8].*

Hence, there is a need to clarify terms and their interpretation.

Figure 1.1. Two understandings of palliative care and relation to time. The top figure demonstrates the earlier understanding and the one at the bottom demonstrates a newer understanding, which is aligned with the WHO's definition of palliative care [6]. (The figures are made with inspiration from Boyd et al. [7])

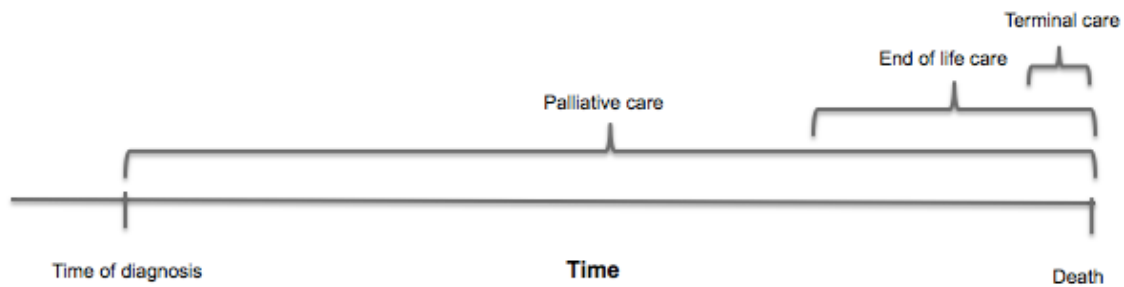


### 1.1.1 Definition of key terms

In this dissertation the terms ‘palliative care’, ‘end-of-life care’, and ‘terminal care’ are used to describe different phases of the palliative trajectory in relation to time (Figure 1.2). It is reasonable to divide the palliative trajectory into different phases because other needs and concerns will emerge as the disease progresses [9, 10]. In this dissertation, the term ‘palliative care’ applies to the entire time span from the time of diagnosis until the time of death. This is concordant with the broad definition suggested by the WHO [2]. As the disease progresses, other needs and concerns will emerge. The term used about the care to meet these needs is ‘end-of-life care’. The ‘end-of-life’ typically covers the part of the palliative trajectory when people are likely to die within 12 months. The definition of end-of-life in this dissertation is inspired by the NICE guideline “End of care for adults” and clinical palliative phases suggested by Dalgaard [11, 12]. However, there is no clear transition between the different phases, and the transition will vary from patient to patient. The care provided in the last part of the trajectory, when death is impending, will be referred to as ‘terminal care’. With regard to who should be offered palliative care, there is increasing evidence that all patient groups benefit from a palliative approach (see section 1.2.3.2 about disease trajectories, page 18).



Figure 1.2. Illustration of how palliative care, end-of-life care, and terminal care are defined in the dissertation in relation to time.



### 1.1.2 End-of-life care

To ensure high quality end-of-life care for patients, it is necessary to focus on what is considered ‘good end-of-life care’ by patients. The literature shows that the patients consistently prioritise freedom of symptoms, a sense of achieving completion in one’s life, taking part in decision-making regarding treatment, being seen as a whole person, and continuity, including a strong patient-physician relationship, as the most important elements in end-of-life care [13-18].

Another quality parameter is the whereabouts of the patient in the last part of the disease trajectory and the actual place of death. Here it has been showed that cancer patients’ preferred place of care at the end of life and place of death is home. For that reason, home death is used as an important parameter in evaluating the quality of end-of-life care, based on the assumption that it is the fulfilment of the preferences of the majority [9]. It is an on-going discussion whether preferences regarding place of care and place of death change when death is approaching. Two recent reviews conclude that end-of-life preferences are stable over time regardless of diagnosis and disease progression but also that more research about place of care and death is needed [19, 20].

Despite most patients’ preferences for home death, the reality in Denmark is that only 29% of all deceased persons died at home in the time span from 2007–2011 [21]. This discrepancy between patients’ preferences and actual place of death is found in most Western countries [22].

The possibility of dying at home depends on different factors; some are related to patients and their family relations, and others are related to the health care system.

Several patient-related factors such as age, gender, marital status, educational background, diagnosis, and length of diseases was been shown to be associated with the possibility of dying at home [23-29] (Table 1.1). However, these identified associations are intermittent and not consistently found to be associated with place of death. When looking at ways to improve end-of-life care it is difficult and often not possible to change the patient-related factors.

*Table 1.1. Patient-related factors associated to the home deaths. The direction of the association between the factor and home death is indicated with + (positive) or – (negative). References refer to studies where significant associations were found.*

Patient-related factors	Associations with home death	References
Age		
high age	-	[24]
50-59 and 70-70 years	-	[27]
Sex		
female	+	[28]
Civic status		
living with relatives	+	[24-26, 28]
being married	+	[23, 29]
Cause of deaths		
malignant diseases	+	(19, 20, 23)
non-malignant diseases	-	[24]
High educational level	+	[24]
High income	+	[27]

An international comparative study found that the availability of GPs, among others things related to the organisation of health care, partly explained some of the variation in places of death between countries [22].

Hence, the following part of the introduction will focus on the GPs as the main providers of basic end-of-life care.

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## 1.2 GPS AND END-OF-LIFE CARE

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### *1.2.1 GPs' relation to end-of-life care*

The involvement of GPs in end-of-life care improves the possibility of dying at home [25, 29-32]. Patients are more likely to die at their preferred place when the GPs know their end-of-life preferences [23, 25, 26].

The provision of palliative care is formally pointed out as one of the GPs' tasks by the European Organisation of General Practice [33]. The GPs take a natural part in the trajectory for several reasons. The way of working in general practice on the basis of the bio-psycho-social model is in good correspondence with the holistic person-centred approach in palliative care [33], and most GPs see palliative care as a natural and rewarding part of their clinical work [34, 35]. The longstanding relationship between GPs, the patients, and their relatives makes it easier to maintain continuity during the disease trajectory. This is highly appreciated by patients and relatives [1, 36, 37]. The GPs' position in the Danish health care system as gatekeepers to specialist treatment enhances their involvement in all of the disease trajectories [37].

### *1.2.2. GPs and home visits at the end of life*

GPs have the possibility to pay home visits to patients for whom it is too difficult to come to a consultation or for whom a home visit is relevant for other reasons. In a palliative context, home visits paid by GPs during daytime is the single item that is consistently and strongly associated with cancer patients' possibilities of dying at home (or inversely associated with dying in hospital) [29, 31, 38]. Nonetheless, the designs of these previous studies do not allow adjustment of an important possible confounding by indication: the home visits paid by the GP could be caused by the fact that the GP knew the patient had a strong preference for dying at home.

Most GPs regard paying home visits as a part of providing good end-of-life care [39, 40]. However, another study has shown that some GPs considered home visits as a barrier to the provision of end-of-life care [34].

It is important to investigate the importance of home visits in end-of-life care, as a reduction in home visits has been seen in Europe within the last decades [41].

### *1.2.3. GPs' knowledge of end-of-life needs and provision of end-of-life care*

It is a prerequisite for the GPs to be able to provide end-of-life care that they are aware of patients with possible care needs, and that they possess skills and knowledge to meet all the different aspects of end-of-life care.

#### 1.2.3.1. Awareness of patients

Awareness of potential care needs at the end of life is closely linked to prognostication of remaining lifetime. Here GPs are inclined to overestimate their patients' expected remaining lifetime [42], which may cause the provision of end-of-life care to be delayed or not provided at all.

Gadoud et al. used the primary care database in the UK to investigate the time point when GPs registered their patients with cancer or heart failure in the palliative register. Cancer patients were 7 times more likely to be registered compared with patients suffering from heart failure. Furthermore, patients with heart failure were registered very late in their trajectory in contrast to cancer patients [43]. The same pattern was found in Denmark when patients registered for drug reimbursement due to terminal illness were identified. Cancer patients were more likely to receive the reimbursement and had a longer survival time after the assignment of drug reimbursement compared with patients with non-malignancies [44]. Patients suffering from non-malignant diseases (defined as all diseases that are not cancer) are less likely to receive end-of-life care, although they have similar prognoses and burden of symptoms as do cancer patients [6, 42, 43, 45-47]. One of the reasons for this disparity in end-of-life care is identified to be caused by different disease trajectories.

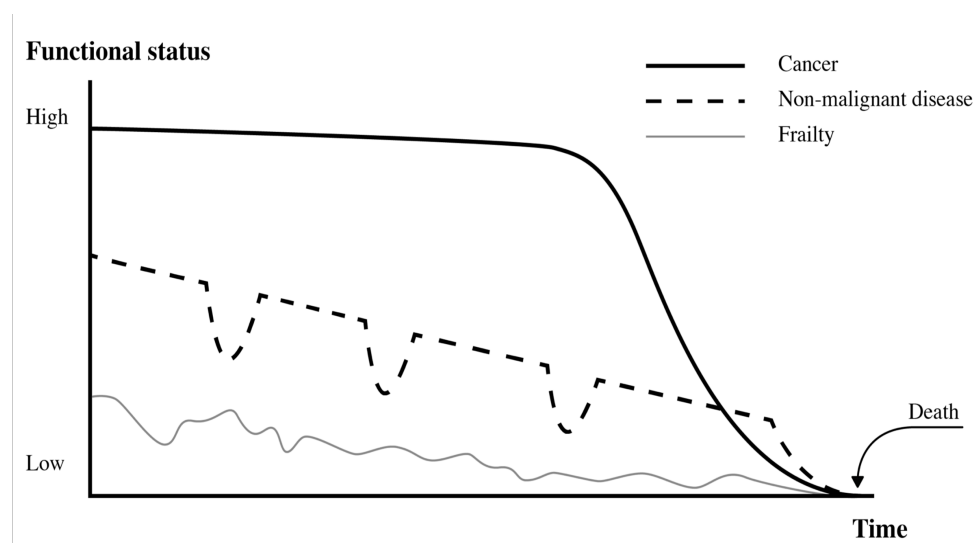
#### 1.2.3.2 Disease trajectories

The different disease trajectories have been sketched out in a theoretical model showing differences in functional status in three different disease groups (cancer, non-malignant diseases, and frailty) in the last year of life [48-50].

These trajectories are shown in Figure 1.3. The trajectories can be characterised as follows:

- A trajectory characterised by a high level of performance and then a precipitous decrease in functional status, indicating a transition in treatment and care (typically cancer patients)
- A trajectory characterised by a steady decline over a long period of time punctuated by repeated exacerbations with acute deterioration and some recovery (typically patients suffering from non-malignant diseases like chronic obstructive pulmonary diseases and heart failure).
- A trajectory with long gradual decline of functional status (typically frail elderly or patients with dementia)

Figure 1.3. Three different disease trajectories based on functional status.



The figure is inspired by Murray et al. [51].

An important difference with regard to the provision of end-of-life care between the disease trajectories is how easily recognised the transition is from palliative care to end-of-life care. A clear transition like the one seen in the cancer trajectory is found to be positively associated with the possibility of dying at home and of hospice care [52].

The gradual decline seen in the trajectory of the non-malignant diseases makes it challenging to identify the right time to initiate the provision of end-of-life care. However, over time the decline in function is apparent. This provides a unique opportunity for the GPs to take an active part in provision of the end-of-life care. Danish patients with chronic non-malignant diseases (e.g. COPD) see their GPs regularly as a part of chronic disease management. This allows the GPs to monitor the disease progression and initiate end-of-life care when relevant. However, it is unknown to what extent Danish GPs are aware of their patients suffering from non-malignancies with potential end-of-life needs, and hence make use of this possibility.

#### 1.2.3.3. Awareness of the patients' needs

##### Freedom of symptoms

For patients a very important issue in end-of-life care is alleviation from symptoms [14]. However poor symptom control has been reported by patients, relatives, and GPs in the general practice setting [35, 36].

##### Key worker

As mentioned above, another important issue for patients is the sense of continuity in the trajectory. Palliative trajectories are often characterised by involvement of many different health care persons in both primary and secondary care. This creates the need for a key worker with a coordinating function for both patients and health care professionals [53]. In the recent clinical guideline for palliative care in general practice, it is suggested that GPs assume the key worker role. A Danish study investigating the key worker in

palliative trajectories found that GPs were seen by patients, relatives, and GPs themselves to be the ideal key worker. However, the study also found that patients and relatives felt they had to assume the role themselves, while at the same time GPs and community nurses felt they were the key workers [54]. Hence, there is a need to establish whether the GPs feel confident and willing to take on the role of a key worker.

#### Proactive approach

The majority of patients in palliative trajectories want the GPs to assume a proactive palliative approach. They expect the GPs to initiate talks about palliative issues at the appropriate time, whereas the GPs are reluctant to do so, as the fear of doing harm to the patient by talking about issues that might upset the patients or make them anxious [39, 55]. This misunderstanding might result in no space being left for end-of-life discussions and lack of end-of-life care. It is uncertain whether such findings apply to a Danish context, and if Danish GPs take on a proactive approach.

#### *1.2.4 GPs' palliative skills*

It is important that GPs possess a whole range of skills, as their awareness of the patients' needs is found to be associated with their skills. The GPs tend to miss symptoms that they do not know how to treat or symptoms that are less common [35].

##### 1.2.4.1 Medical skills

GPs need to have medical skills to release the patients from symptoms, which is considered one of the most important aspects of palliative care. Over time, an improvement in pain management has been seen in general practice [35]. However, GPs and relatives still identify a lack of medical skills in palliative care [56-58]. GPs recognise the need to improve medical skills because pain management is requested as a topic in palliative care education [59]. Furthermore, studies have shown that the majority of GPs feel uncomfortable with the more technical aspects of pain management, such as the use of syringe drivers and subcutaneous needles for pain treatment [34, 58, 60]. Syringe drivers and subcutaneous needles are used in the terminal phase to administer medicine in a gentle way. Consequently, these medical skills are often prerequisite to the patient's possibility to remain at home at the end of life.

##### 1.2.4.2 Psychosocial and spiritual skills

GPs report that they have less confidence in dealing with the patients' psychosocial issues when they report the level of confidence themselves [34] or are interviewed about specific cases [61]. In a Danish study, patients with palliative needs stated that they lacked support from their GPs, especially on social issues [62]. A qualitative study investigated the GPs' spiritual skills and found that GPs recognised the importance of spiritual needs but were reluctant to raise spiritual issues themselves [63].

It is unknown how confident and skilled Danish GPs are in the provision of end-of-life care, especially in skills other than medical skills.

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### 1.3 SUPPORT TO GPs IN THE PROVISION OF END-OF-LIFE CARE

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Approximately 51,000 people die every year in Denmark. There are 3600 Danish GPs, so GPs have on average 14 of their patients dying every year of all causes [37, 64]. This makes it challenging for GPs to maintain palliative skills and keep their palliative knowledge updated [57].

Variation and lack of awareness have been found in Denmark with regard to different patient groups, end-of-life care skills, and knowledge. Hence, there is a need to support GPs to ensure an equal provision of end-of-life care.

In order to optimise end-of-life care, the GPs need to improve their skills and change clinical practice. This can be a challenging process especially as many GPs work independently.

A tailored complex intervention taking the context and the target population into account makes a change more likely [65]. Several interventions consisting of different components have been tested and found to be working in different ways with different effects on clinical behaviour [66].

#### *1.3.1 Continuing Medical Education*

Continuing medical education (CME) sessions and electronic decision support (EDS) have previously been shown to be effective individually in changing clinical practice in medical topics, including palliative care [66-71]. The CME sessions were found to be valuable in introducing new knowledge and facilitating change of attitude but had a low direct impact on clinical practice [66]. A CME session used in a palliative context increased the GPs' confidence in carrying out tasks; however, it did not improve clinical tasks performed such as pain assessment and opioid prescription [72].

#### *1.3.2 Electronic Decision Support*

An EDS with a reminder function was found to be useful in changing diagnostics and preventive care [66]. In a palliative context, EDS tools have enhanced the identification of patients with potential palliative needs by searching electronic patient records [73]. An important barrier for the use of EDS in a palliative context has been identified, as some GPs were reluctant to register the computer-identified patients as 'palliative' due to associations with death and dying [73]. This enhances the need for a change in attitude and understanding of palliative care alongside the implementation of an EDS.

Hence, an intervention consisting of CME and EDS could be a way to optimise the provision of end-of-life care by GPs.

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### 1.4 BACKGROUND AT A GLANCE

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- GPs are crucial in basic palliative care as they are responsible for at-home care.
- Home visits paid by GPs are found to be strongly associated with patients' possibility of dying at home. However, these previous findings are subjected to confounding by indication.

- GPs want to and are expected to assume the role as key worker, but knowledge is lacking regarding whether they feel confident and skilled enough to fulfil that role.
- There is a need to optimise basic palliative care. Complex tailored intervention has proved to be effectual in changing clinical practices in other medical fields. However, it remains uncertain whether it is effectual in changing palliative care.

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## 1.5 AIMS OF THE DISSERTATION

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The overall aim of this dissertation was to investigate different aspects of end-of-life care in general practice. The following research questions were addressed:

Research question A:

Are home visits paid by GPs associated with their cancer patients' place of end-of-life care and place of death?

Research question B:

In which issues do Danish GPs need support in the provision of end-of-life care? Is it possible to develop an intervention that supports GPs' in the provision of end-of-life care?

These research questions were investigated in three papers with the following aims:

Paper I

The aim was to assess the association between the GPs' propensities to pay home visits in general and their cancer patients' likelihood of avoiding hospitalisation the last three months of life and for dying out of hospital.

Paper II

The aim of this study was to assess to what degree GPs report providing end-of-life care with regard to patients with different diseases, their confidence with being a key worker, their organisation of end-of-life care, and their medical and psychosocial end-of-life care skills. Furthermore, we aimed to analyse whether specific characteristics of the GPs and their practices were associated with their perceived abilities to provide end-of-life care

Paper III

The aim of this study was to develop and pilot-test an intervention consisting of a Continuing medical education session and electronic decision support to support the end-of-life care in general practice for patients with cancer or chronic obstructive pulmonary disease.

# **CHAPTER 2:**

## **METHODS AND MATERIALS**

This chapter outlines methods of the three papers as well as a description of the data



First, the setting of the work carried out in this PhD project dissertation will be outlined followed by an overview of the different designs in the three papers. The methods will then briefly be outlined for each paper separately. Finally, a description of data, data sources, and their use in the papers is given.

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## 2.1 SETTING

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### 2.1.1 The Danish health care system

The Danish health system is predominantly tax-financed and provides free access to most health care services for all Danish residence. The health care system is organised into primary and secondary healthcare. Primary care deals with general health problems and day-to-day care. Primary care is provided to the patient in the community when the patient is at home by healthcare professionals such as GPs, physiotherapists, and community nurses. The primary care is the principal point of care within the health care system. Secondary care is provided at hospitals at both general and highly specialised departments.

Palliative care in Denmark is organised in a similar way: in basic and specialist care. The basic care is provided by health care persons with main tasks other than palliative care, e.g. GPs, community nurses, and general departments in hospitals. Theoretically, this means that every patient with palliative needs receives a minimum of basic palliative care; however the extent of provision of basic palliative care is unknown, because it is not registered.

Some patients develop complex palliative needs (physically, emotionally, socially, and/or spiritual) during the trajectory that cannot be handled on the basic level. In such cases, patients will be referred to specialist palliative care either by their GP or a physician working in the general wards at the hospitals. Health care professionals who work exclusively with the provision of palliative care are providers of specialist palliative care. The Danish specialist palliative care is based on outgoing teams, palliative departments, and hospices. Central Denmark Region has currently five hospices and five outgoing teams based on five different hospitals distributed throughout the region [74]. If a patient receives specialist palliative care from an outgoing team, it ideally works as a co-operation, with shared care between the primary health care providers and the palliative team.

### 2.1.2 Danish GPs

There are approximately 3600 GPs in Denmark who works independently either solo in their own practices or in a shared practice. A general practice has on average 1600 patients listed, and 98% of the Danish population is listed with a general practice [37]. The GPs have the medical responsibility for the at-home care for patients on their list. They provide most of the care themselves but have access to advice from specialist in all medical fields and can refer patients to specialist treatment in their function as gatekeepers [37]. The GPs' work is remunerated through a unique provider number with a mixed capitation and fee-for-service system [37].

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## 2.2 OVERVIEW OF THE PAPERS

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The three papers differ in design, population, data sources, exposure, and outcomes. Table 2.1 provides an overview of these differences.

Table 2.1. Overview of characteristics of the methods used in the three papers

Paper	Design	Study population	Data source	Exposures	Outcomes
I	Cohort study with an ecological exposure	Deceased cancer patients died 2004-2012	Register data on patients listed at a general practice in Denmark from 2003-11 and deceased patients from 2004-2012 (NPR, HSR, PL, DST)	General practices' propensity to pay home visits during daytime.	Proportion of cancer patients dying at home and number of bed-days they spent in hospital the last three months of their life
II	Cross-sectional study	GPs in Central Denmark Region	Questionnaires, register data on GP characteristics		Answers to items about confidence and skills in the provision of end-of-life care
III	Development of an intervention-study	GPs in Central Denmark Region	Questionnaires, interviews, participation rate, GPs characteristics, sign-up rate	Three phases of development: identification of evidence, modelling, piloting of the intervention	Identified evidence, the content of the components of the intervention, the process evaluation of the piloting

*GPs: general practitioners; NPR: the Danish National Patient Registry, HSR: the Danish National Health Service Registry, PL: patient list; DST: statistics Denmark*

## 2.3 PAPER I

### 2.3.1 Study design

A nation-wide register-based observational cohort study with an ecological exposure. The study was carried out in two steps. The first step was the calculation of the exposure: general practices propensity to pay home visits. The second step was calculation of the association between the practices' propensity to pay home visits the preceding year and their cancer patients' likelihood for avoiding hospitalisation in the last three months of their life and for dying at home.

### 2.3.2 Study participants

The cohort for the first step consisted of all Danish citizens in 2003 listed at an active general practice in the time span 2003-2011. The persons were included in the study population if they were 40 or above at the beginning of the study or else when they turned 40 years in the study period (2003-2011). Included persons contributed with person year to the practice where they

were listed from time of inclusion until either leaving the list system, emigration, termination of study, or death, whichever came first. For this study a practice was defined as 'active' from the year following the first home visit to the included persons until the last whole calendar year before the last home visit. This restriction was done as the first and the last year a practice was active might deviate from other years due to start up and phasing out.

The cohort for the second step comprised persons from cohort 1 who died in a natural manner (excluding murder, violence, accidents, and suicides) from 2004 to 2012 due to cancer as a cause of death stated on the death certificate. To be included, the deceased patients had to be listed at the same practice for at least six months prior to death. This limitation was chosen to make an acquaintance between patient and GP possible.

### 2.3.3 Exposure

The exposure was the GPs propensity to pay home visits. It was calculated as a standard incidence rate (SIR): observed home visits over expected home visits in relation to the total number of observed person years in the practice. Expected home visits were estimated based on the composition of a practice's patient population. The practices were then ranked according to their SIR and categorised into four groups based on quartiles. These four groups comprised the exposure.

Home visits were included if they were paid by a general practitioner during daytime (between 8 am and 6 pm Monday-Friday) to ensure the home-visits were paid by the patient's GP.

### 2.3.4 Outcomes

The outcomes were number of bed-days in hospital during the last three months of the patients' life and death out of hospital/hospice for the deceased cancer patients. They were chosen as proxies for good end-of-life care in accordance with the patients' preferences (see Introduction, section 1.1.2, page 16) The bed-days were grouped based on quartiles to be three bed-days or less (1<sup>st</sup> quartile) and 20 bed-days or more (3<sup>rd</sup> quartile). Death out of hospital was in this study defined as when death occurred anywhere apart from hospital/hospice. The variable was dichotomised.

### 2.3.5 Statistical analyses

The statistical analysis was done in two steps. The first step in the analysis was the calculation of a practice's propensity to pay home visits, which was estimated using their SIR. Poisson logistic regression was used to calculate the expected number of home visits on the basis of the composition of the patient population in the practice including patients' age, educational level (<10 years, 10–15 years, >15 years), degree of urbanisation (based on the definition of degree of urbanisation from UN [75] and regrouped as follows: Capital city, >50,000, 10,00-49,999, 200-999, < 200), and the patients' comorbidity (Charlson comorbidity index 0,1-2 or  $\geq 3$ ). For an overview of how conditions were scored and contributed to the calculation of the Charlson index, (see supplementary material in Table 2 of Paper I, page 102).

The patients in the four propensity groups were compared using descriptive statistics and the average number of hospital admissions during the last three months of life for each of the four groups was calculated.

In the second step logistic regression was used to examine the associations between the GPs' propensity to pay home visits and palliative outcomes. The numbers of bed-days were

transformed into binary variables based on the first quartile (0-3 bed-days/more) and the third quartile (20-91/less bed-days). The association between home visits and bed-days in hospitals in end of life was adjusted for age, degree of urbanisation, calendar year, and comorbidity. The association between home visits and home deaths was adjusted for patient age, degree of urbanisation, calendar year, comorbidity, and civil status. For these analyses, cancer diagnoses were excluded from the calculation of Charlson comorbidity index.

Subsequent analyses were performed to investigate the importance of the proportion of missing values regarding place of death. Finally, to test for a possible interaction of degree of urbanisation, the analyses were repeated for every degree of urbanisation.

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## 2.4 PAPER II

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### 2.4.1 Study design

We conducted a cross-sectional questionnaire study to investigate the GPs' self-perceived confidence and skills in provision of end-of-life care.

### 2.4.2 Study participants

All 843 GPs working on contract with the Central Region Denmark on the 1st of March 2014 were approached by mail with a questionnaire. If unanswered, a reminder was sent after three weeks. The GPs were compensated with 122 DDK for taken time to fill out the questionnaire. In all, 573 GPs (68%) returned a questionnaire.

### 2.4.3 Outcomes

The outcomes were the answers to the items in the questionnaire. To our knowledge, there was no existing tool available at the time to examine self-perceived confidence and skills in providing palliative care, so a questionnaire was developed.

First step of designing the questionnaire was to identify which items to cover. This was done by a narrative literature search in the medical databases: Biblioteket.dk, Swemed, Pubmed, Embase, Sinahl. The searches were first done using medical subheading (e.g. MeSH in Pubmed).

An example of a search is illustrated below:

(General practitioner OR physicians, family OR General practice) & (palliative care OR terminal care OR end of life care)

These searches were followed by searches using free text using terms like "confidence" and "skills". The final decision about which items to cover was made in the research team after discussions drawing on the identified evidence and previous experience within the group. The chosen items are listed in Table 2.2.

The questionnaire was pilot tested among 20 GPs. After the pilot test, minor changes were made, mainly concerning wordings. The final questionnaire consisted of 29 items on six predefined

themes and included both previously used questions and ad hoc items (see the questionnaire in Danish in appendix 1, page 162).

*Table 2.2. The main themes, sub-themes, and items in the development of the questionnaire.*

Main themes	Sub-themes	Items
Awareness of patients		How often do you offer palliative care to cancer patients How often do you offer palliative care to patients suffering from chronic obstructive pulmonary disease How often do you offer palliative care to patients suffering from heart failure How often do you offer palliative care to patients suffering from neurological diseases How often do you offer palliative care to patients suffering from dementia
Being a key worker	Confidence	I feel confident being the key worker in palliative trajectories How skilled do you feel providing palliative care compared to your colleagues
	Proactive	I am proactive in identifying patients with palliative needs I take the initiative to talk to my patients about dying
	Know patient's preferences	I know where my patients suffering from severe disease want to die
Organisation		I have my patients with palliative needs listed I am available out-of-hours for my patients with palliative needs It is difficult to find the time to provide palliative care in my work I have a set of procedure for providing palliative care
Palliative skills	Medical	I feel confident treating pain I feel confident treating dyspnoea I feel confident treating nausea/vomiting I feel confident treating obstipation
	Terminal phase	I feel confident using the just-in-case box I feel confident administering medicine subcutaneously
	Psycho-social	I feel confident taking care of the psychological situation I feel confident taking care of the social situation I feel confident taking care of the relatives
Co-operation	The relatives	I actively engage the relatives in anticipatory care planning
	The community nurses	I actively engage the community nurses in anticipatory care planning It is easy to cooperate with community nurses
	The palliative care teams	It is easy to get advice from the palliative team It is easy to cooperate with the palliative team
Barriers		What do you see as the three main obstacles to the provision of palliative care in general practice?

#### 2.4.4 Statistical analyses

Descriptive statistics was used to describe characteristics of responders and non-responders, and the responders' perception of provision of end-of-life care. The responders and non-responders

were compared using the chi-square test, the Mann-Whitney test, or the Kruskal-Wallis test, whichever was appropriate. The consistency in the GPs' answers to the items about awareness and pro-activeness was tested using weighted kappa coefficients [76].

Logistic regression was performed to describe associations between five selected items (awareness of end-of-life needs, confidence being a key worker, skills in the provision of end-of-life care, and organisation of end-of-life care) and GP characteristics (age, gender, list size, organisation, and urbanisation). The variables used to characterise the GPs were tested for collinearity using Pearson's correlation coefficients, and the questionnaire answers were dichotomised (agree/strongly agree vs. neither nor/disagree/strongly disagree) before the regression analysis was performed. Finally, a correction was performed regarding the effect of clustering by performing robust variance estimation.

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## 2.5 PAPER III

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### 2.5.1 Study design

The design in Paper III is an intervention study. The guideline from the Medical Research Council (MRC) [77, 78] on Complex Intervention was used to develop and design the intervention. Our study comprised the first three close-knit phases of the development process: identification of evidence base and relevant theory (Phase 0), modelling of intervention (Phase 1), and pilot testing of the intervention (Phase 2).

#### Phase 0

Identification of evidence base and theory about barriers and facilitators to the implementation of end-of-life care in a general practice setting was done through narrative literature searches with two foci: barriers to end-of-life care and facilitators to change clinical practices. To adapt the established knowledge to the setting, three unstructured interviews were performed with GPs with special interest in end-of-life care. The barriers and facilitators were discussed within the research group. Consensus was reached as to which barriers to address and which facilitators of change to use.

#### Phase 1

The intervention was modelled on the basis of the evidence-base identified in phase 0 and adapted to a Danish setting by the research group drawing on its own experiences. The intervention consisted of two components: a CME session and an electronic decision support (EDS). Two working groups including stakeholders were appointed to work on each of the components to ensure their usability and ease of implementation. The Danish clinical guideline on palliative care in general practice [79] was used as the medical curriculum in both working groups. The group developing the CME session was comprised of the research group (two researchers with special interest in general practice, an oncologist, and specialist in palliative care), a GP responsible for the regional CME, and two academic coordinators for CMEs targeting GPs in the region. The EDS working group consisted of the research group, two GPs, and technical staff from the Danish Quality Unit of General Practice (Dansk Almenmedicinsk KvalitetsEnhed (DAK-E)).

Apart from the work in the working group, two successive meetings were held during the development process of the EDS, with participation from the GPs engaging in CME, administrative staff from all regions in Denmark, and a member of the research group (AKW). The EDS was based on existing technology to ensure compatibility with all electronic patient record systems in Danish general practices [37, 80]. The technical development was carried out by DAK-E.

Phase 2: The intervention was pilot-tested on 843 GPs in the 407 practices in the Central Denmark Region. The pilot test was systematically evaluated using process evaluation inspired by the MRC guideline and Grol et al. [66, 81]. The evaluation of the intervention focused on the fidelity, quality, and context.

The *fidelity* was assessed by focusing on the adherence to the blueprint and the reach of the intervention (if the target population was reached). The *adherence to blueprint* examines to what extent the components of the intervention were delivered as intended. It also encompasses whether the development and implementation of the components succeeded. The *reach* of the intervention was assessed by the rate of attendance for the CME session and sign-up rate for the EDS. Additionally, by comparing GPs characteristics of the four following groups of GPs: those who attended in the CME session, those who signed up for the EDS, those who did both, and those who did neither.

The *quality* of the intervention was assessed separately for the CME and the EDS. The quality of the CME was assessed using the GPs' experience and their perception of the effect of the CME session. This was investigated by an independent evaluation unit from the Central Denmark Region using two methods: a questionnaire survey carried out after each CME session and interviews with the focus group (three GPs) performed straight after three of the six sessions. The evaluation focused on: benefits of participating in the CME session, if and how the CME had an impact on the clinical work, the teaching method, and suggestions for improvement of the CME session.

To assess the experience of the EDS, a postal questionnaire was planned to be distributed one year after the implementation. Furthermore, the quality of the identifier function in the EDS (see result section, page 42) was to be examined using register-based data.

The short-term impact of the CME session was assessed by approaching participating GPs by mail three month after the session asking "Have you changed anything in your approach to palliative care since the CME? (If *yes* then what/if *no* then why not?)". One year after the implementation, an overall assessment of the impact of the intervention was planned using register-based patient related outcomes (e.g. number of home deaths).

The *context* element focused on factors that could have facilitated or hampered the effect of the intervention. This was assessed by the research group focusing on the context of general practice it-self as well as focusing on possible time-specific circumstances.

### 2.5.2 Statistical analyses

The statistical analysis used in this study is descriptive analysis with regard to the attending GPs and their answers to the questionnaires after the CME.

## DATA

All the three studies used data from some of the national or regional registers. The following section is a short presentation of the registers from where the data were extracted and how data were used in each of the studies.

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## 2.6 THE REGISTERS AND DATA BASES

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### 2.6.1 The Danish civil registration system and the CPR number

In Denmark, it is possible to do register-based research on an individual level due to the Danish unique personal identification number (the CPR number). The unique number is assigned to every individual either at birth or immigration. Hence, every person with permanent residence in Denmark is registered in the Danish Civil Registration system by that unique identifier [82]. The CPR number is used in all contacts with public authorities including the health care system. This allows exact linkage between national registers, which was used in Paper I.

### 2.6.2 The National Patient Register

The register contains information about all non-psychiatric hospitalisation (since 1977) and outpatient visits (since 1995) in Denmark. The records hold information about CPR number, date of admission and discharge, surgical, and procedure codes as well as up to 20 diagnoses (coded using the international Classification of Diseases coding system (ICD) version 10 since 1993) [83]. For Paper I, diagnoses (primary and secondary) were retrieved for every person to calculate the Charlson comorbidity index (CCI). We retrieved data about number of bed-days three months prior to death for all deceased persons from 2004 to 2012, which was used as secondary outcome in Paper I.

### 2.6.3 The Danish Register of Death causes

Data were retrieved from the death certificates filled out when death occurs. If death occurs in hospital, a physician fills out the certificate. If death occurs out of hospital, either a GP or a hospice physician fills out the certificate. The register contains data about the deceased patient (sex, unique personal number, date of death), place of death (hospital/hospice, residence, known address, unknown address), manner of death (natural cause, accident, homicide, and suicide) and cause of death [84]. Since 2007, it has been mandatory to fill out the certificate electronically. Data about cause of death (cancer or not) and place of death (home or not) were retrieved for Paper I.

### 2.6.4 The Danish National Health Service registers

The National Board of Health is in charge of the Danish National Health Service registries, which contain registration about all activities of health professional (i.e. GPs and private practicing medical specialists). Every encounter between patient and GP and procedures related to these encounters form the basis of the remuneration [85]. For Paper I, information about all home visits paid by GPs during daytime to patients aged 40 or above was retrieved.

### 2.6.5 Statistics Denmark

Statistic Denmark is a national institution responsible for collecting, maintaining, processing, and providing statistics data concerning Danish society from many different public registers [86]. For Paper I, data were retrieved about educational level (highest completed educational level), civil status (single, married), income level (disposable household income), and degree of urbanisation (based on population density). Data from Statistics Denmark were used in Paper I.



### 2.6.6 Provider number and the Patient List Register

Every general practice has its unique provider number if they have contract with the tax-based health insurance system. The provider number is used for remuneration and is a unique identifier.

This enables retrieval of anonymised information about a general practice and its activities. However, as the GPs are allowed to share provider number or sell it to another, it is impossible to get data on an individual GP level by using the provider number.

The regions in Denmark have up-date administrative registers about the practices in their region.

The Patient List register contains information about affiliation to a practice for every Danish citizen. This allows exact linkage at any time between persons (using the CPR numbers) and general practices (using the provider number).

In Paper I, data from the Patient List register were used to link patients to practices. In Papers II and III, background characteristics (organisation of practice, gender, and age) of the GPs in the Central Denmark Region were retrieved using the provider number from the Central Denmark Region's register.

### 2.6.7 The DAK-E and the DAMD- data base

'Dansk Almenmedicinsk KvalitetsEnhed' (DAK-E) is a national unit working with quality in General Practice through data-collection via the electronic health record systems. A national database for general practice (Dansk Almen Medicinsk Database (the DAMD)) for general practices was in the planning stage. Its aim was to comprise data about prescribed drugs in general practice, National Health Service disbursement codes, results of laboratory analysis, and ICPC diagnosis. Furthermore, it should be possible to collect additional information for specific research project through pop-up windows filled in by the GPs [87]. However, the data collection for the database was restricted due to legal issues. This restriction of data collection had a huge impact on Paper III: the EDS was designed to work on data collected from the electronic patient record, which became impossible. Hence, we had to shut down the EDS earlier than expected. Furthermore, the evaluation of the EDS was partly based on information about sign-up rates and the use of the pop-up window, which became inaccessible due to the untimely closing of the DAMD.

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## 2.7 DATA ENTRY AND STORAGE

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The anonymised data for Paper I were stored electronically at Statistics Denmark and was only accessible via a personal secured virtual private network (VPN).

Questionnaires used in Paper II were designed and processed in Teleform® Enterprise version 8.0. This has been found as valid as manual registration [88]. An assistant scanned and verified all returned questionnaires. If there was doubt about an answer, it was discussed between AKW and the assistant. The data were transferred to a statistical software program STATA® [89] and were stored in a secure database at The Research Unit of General Practice at Aarhus University.

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## 2.8 SIGNIFICANCE LEVEL AND STATISTICAL SOFTWARE

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The level of statistical significance was 5%, and 95% confidence intervals were stated as 95%CI when relevant. The software used for processing of data in Papers I and II was Stata® 13 [89], and Excel was used to the descriptive statistics in Papers II and III [90].

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## 2.9 RESEARCH APPROVALS

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Paper I: According to Scientific Ethics Committee for the Central Region of Denmark, this study did not need the approval of the Scientific Ethics Committee (Report no. 31/2013). The study was approved by the Danish Data Protection Agency (J.nr. 2013-41-1965)

Papers II and III: According to the Scientific Ethics Committee for the Central Region of Denmark, the Biomedical Research Ethics Committee System Act does not apply here (31/201). The study was approved by the Danish Data Protection Agency (J.nr. 2013-41-1965) and was registered in [clinicaltrials.gov](http://clinicaltrials.gov) (identifier: NCT02050256). The Multi-Practice Committee of the Danish Society of General Practitioners and the Organization of General Practitioners in Denmark (MPU 02-2014) recommend participation in both studies to the GPs.



# **CHAPTER 3:**

## **RESULTS**

This chapter offers a summary of the main results presented in the three papers of this dissertation. A more detailed presentation of the results can be found in the individual papers.

### 3.1 PAPER I

#### 3.1.1 Characteristics of the cohorts

In total, 2670 general practices were included. They had a total of 2,518,091 patients listed at the age of 40 or above (cohort 1), making the total observation time 18,364,679 years. During the study period, the GPs paid 727,457 home visits (see Table 1 in Paper I, page 98). The variation was 6.6-fold between the group of GPs with lowest propensity (Group 1: standard incidence rate (SIR): 0.50) and the group of GPs with the highest propensity (Group 4: SIR: 3.28). The patient populations in the different propensity groups were comparable with regard to patient population on all variables (age, gender, comorbidity, income, and educational level) apart from degree of urbanisation. Concerning the degree of urbanisation, there was a tendency towards the group with lowest propensity had more patients living in urban areas than the other groups.

During the study period, 116,677 persons died of cancer (cohort 2). The composition of the deceased patients in the different propensity groups showed the same pattern as in cohort 1.

#### 3.1.2 Hospitalisation at the end of life and place of death

We found a dose-response-like association between the GPs' propensity to pay home visits and their patients' likelihood for avoiding hospitalisation at the end of life and for dying out of hospital. The adjusted OR for having three bed-days or less was 1.13 (95%CI: 1.08; 1.17) when patients listed with GPs with the highest propensity (Group 4) were compared to patients listed with GPs with the lowest propensity (Group 1) (see Table 3 in Paper I, page 100). Patients listed with GPs in Group 4 had furthermore lower odds of having 20 or more bed-days, OR 0.95 (95%CI: 0.91-0.99), compared with patients listed with GPs in Group 1. For patients in Group 4, the OR for dying out of hospital/hospice was 1.20 (95%CI: 1.16; 1.24) compared with Group 1.

Subsequent analyses were made with three different foci to investigate potential bias. We investigated the importance of the uneven distribution of missing values in two ways. Firstly, we repeated the analyses in three different time periods: before (2003-2006) and after the introduction of the electronic death certificate (2007-2008, 2010-2012), and the year all data were manually registered (2009) (Table 3.1).

*Table 3.1. The associations in OR with 95%CI between the GPs' propensity to pay home visits and for dying out of hospital/hospice in three different time period (n=116,677)*

	Group 1 (lowest)	Group 2	Group 3	Group 4 (highest)
Deceased patients 2003-2006				
OR, unadjusted (95%CI)	1 (reference)	1.12 (1.05; 1.18)	1.18 (1.12; 1.25)	1.21 (1.14; 1.29)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.17 (1.10; 1.24)	1.23 (1.16; 1.30)	1.25 (1.18; 1.33)
Deceased patients 2009				
OR, unadjusted (95%CI)	1 (reference)	1.08 (0.97; 1.19)	1.03 (0.93; 1.14)	1.17 (1.05; 1.29)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.08 (0.98; 1.19)	1.03 (0.93; 1.14)	1.16 (1.05; 1.29)
Deceased patients 2007- 8, 2010-12				
OR, unadjusted (95%CI)	1 (reference)	1.09 (1.04; 1.14)	1.14 (1.09; 1.20)	1.23 (1.17; 1.29)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.09 (1.04; 1.14)	1.14 (1.09; 1.20)	1.22 (1.17; 1.28)

*95%CI: 95% confidence interval, <sup>1</sup>adjusted for calendar year, patient age, civil status, and degree of urbanisation.*

Overall, the same pattern was seen in the three time periods with a dose-response association between propensity to pay home visits and dying out of hospital. An exception was seen in 2009.

The distribution of place of death among the deceased cancer patients from 2004 to 2012 is shown in Table 3.2.

Secondly, we repeated the analyses with different ways of operationalizing place of death to see whether the missing values had an impact on the associations. The additional outcomes were home deaths and home deaths including missing values (Table 3.3).

*Table 3.2. Place of death for all included deceased cancer patients in per cent (n=116,677)*

Hospital/hospice	56.1
Residence <sup>1</sup>	31.4
Known address <sup>2</sup>	4.0
Unknown address	0.2
Missing	8.3

<sup>1</sup>residence includes home and nursery home

<sup>2</sup>address of death was known e.g. home of a relative

*Table 3.3. The associations in OR with 95%CI between the GPs propensity to pay home visits and three different outcomes for place of death: dying at home (31.4%), dying at home + missing values (39.7), and dying out of hospital (43.9%) (n=116,677)*

	Group 1 (lowest)	Group 2	Group 3	Group 4 (highest)
Dying at home				
OR, unadjusted (95%CI)	1 (reference)	1.13 (1.09; 1.18)	1.17 (1.13; 1.21)	1.21 (1.16; 1.25)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.09 (1.04; 1.13)	1.13 (1.09; 1.18)	1.17 (1.12; 1.22)
Dying at home (incl. missing values)				
OR, unadjusted (95%CI)	1 (reference)	1.12 (1.08; 1.16)	1.14 (1.11; 1.18)	1.19 (1.14; 1.23)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.08 (1.04; 1.12)	1.11 (1.07; 1.15)	1.16 (1.12; 1.20)
Dying out of hospital/hospice				
OR, unadjusted (95%CI)	1 (reference)	1.11 (1.08; 1.16)	1.16 (1.12; 1.20)	1.23 (1.19; 1.27)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.08 (1.04; 1.11)	1.12 (1.08; 1.16)	1.20 (1.16; 1.24)

<sup>1</sup>adjusted for calendar year, patient age, civil status, and degree of urbanisation

There were no considerable differences between the three different outcomes, as the OR between patients in Group 1 and 4 was 1.17 (95%CI:1.12; 1.22) and 1.20 (95%CI: 1.16; 1.24) for dying at home or out of hospital/hospice, respectively. Finally, we tested the association for interaction of degree of urbanisation (Table 3.4).

Table 3.4. The associations in OR with 95%CI between the GPs' propensity to pay home visits and for dying out of hospital/hospice in five areas with different degree of urbanisation\* (n=116,677)

	Group 1 (lowest)	Group 2	Group 3	Group 4 (highest)
Capital region (n= 22,087 deceased cancer patients)				
OR, unadjusted (95%CI)	1 (reference)	1.09 (1.01; 1.17)	1.16(1.08; 1.26)	1.23 (1.14; 1.33)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.08 (1.00; 1.17)	1.16(1.07; 1.25)	1.22 (1.13; 1.31)
>50,000 (n=15,176 deceased cancer patients)				
OR, unadjusted (95%CI)	1 (reference)	0.99 (0.91; 1.09)	1.11 (1.01; 1.22)	1.19 (1.08; 1.30)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	0.99 (0.91; 1.07)	1.11 (1.01; 1.21)	1.18 (1.07; 1.29)
10,000-49,999 (n=27,370 deceased cancer patients)				
OR, unadjusted (95%CI)	1 (reference)	1.12 (1.04; 1.20)	1.19 (1.13; 1.28)	1.21 (1.12; 1.30)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.11 (1.04; 1.20)	1.19 (1.11; 1.28)	1.21 (1.12; 1.30)
1,000-9,999 (n=29,924 deceased cancer patients)				
OR, unadjusted (95%CI)	1 (reference)	1.10 (1.03; 1.17)	1.12 (1.04; 1.19)	1.16 (1.08; 1.24)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.09 (1.02; 1.17)	1.11 (1.04; 1.19)	1.15 (1.07; 1.24)
<999 (n=21,849 deceased cancer patients)				
OR, unadjusted (95%CI)	1 (reference)	1.06 (0.98; 1.15)	1.06 (0.98; 1.14)	1.28 (1.18; 1.39)
OR, adjusted <sup>1</sup> (95%CI)	1 (reference)	1.06 (0.99; 1.16)	1.06 (0.98; 1.14)	1.28 (1.18; 1.38)

\*based on locality defined as a distinct population cluster, 95%CI: 95% confidence intervals

<sup>1</sup>adjusted for calendar year, patient age, civil status, and degree of urbanisation.

The overall pattern with a dose-response association was seen in every degree of urbanisation, and there was no indication of any interaction. However, not all these subsequent analyses reached statistical significance due to the lower number of patients in each group, but since the trend is the same as in all the other analysis, it does not affect the overall interpretation.

## 3.2 PAPER II

The total response rate on the postal questionnaire was 68% (573 GP) after one reminder had been sent out after three weeks.

### 3.2.1 Provision of end-of-life care to different patient groups

The majority of GPs (82.2%) were offering end-of-life care often/always to their cancer patients. There were considerably fewer GPs who always/often provided end-of-life care to their patients suffering from COPD or heart failure, 38.9% and 36.3%, respectively. There was a higher agreement between regular provision of care to patients with COPD and heart failure ( $kappa$ : 0.740) than cancer and COPD or heart failure ( $kappa$ : 0.21 and 0.17, respectively).

### 3.2.2 Confidence about being key worker

The percentage of GPs who felt confident/very confident about being a key worker was 76%. However, the percentage of GPs who reported that they felt confident/very confident carrying out important key worker tasks (e.g. having a proactive approach and knowing the individual patient's end-of-life preferences) was smaller (Table 3.4). Furthermore, there was low agreement between the GPs' answers regarding their confidence in carrying out the different related tasks.

Table 3.4: The distribution of answers according to confidence and different elements about being a key worker. (N= 571 GPs).

	I feel confident about being a key worker in palliative trajectories		I am proactive in identifying patients with palliative needs		I take the initiative to talk to my patients about dying		I know where my patients suffering from severe disease want to die	
	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)	n	% (95% CI)
Strongly agree	141	25.3 (21.7; 28.9)	82	14.7 (11.7; 17.6)	69	12.3(9.6; 15.1)	50	9.0 (6.6; 11.3)
Agree	284	51.0 (46.8; 55.2)	252	45.1 (40.9; 49.2)	256	45.8 (41.7; 50.0)	260	46.6 (42.4; 50.7)
Neither nor	114	20.6 (17.1; 23.8)	170	30.4 (26.6; 34.2)	187	33.5 (29.5; 37.4)	202	36.2 (32.2; 40.2)
Disagree/ strongly disagree	18	3.2 (1.8; 4.7)	55	9.8 (6.3; 10.9)	47	8.4 (6.1; 10.7)	46	7.5 (5.3; 9.7)
Total <sup>1</sup>	557	100	559	100	559	100	558	100

<sup>1</sup>Missings excluded

### 3.2.3 Organisation of end-of-life care

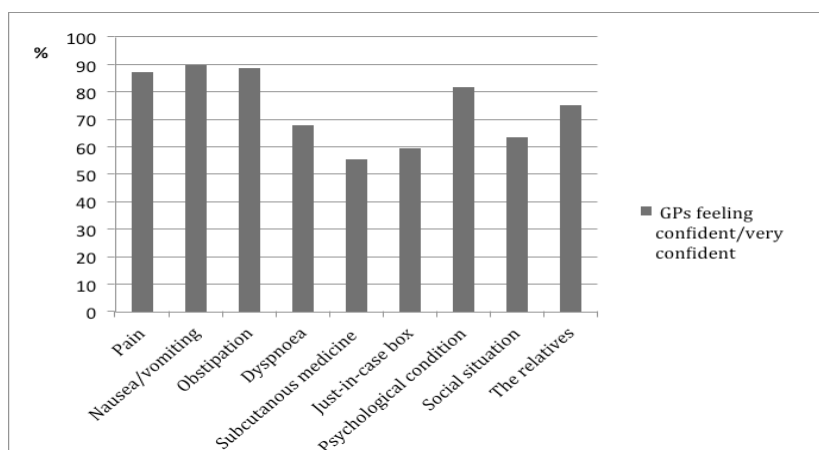
End-of-life care was not systematically organised in general practice. A minority of 9% of GPs kept a register of their patients with palliative needs, and 19% had specific end-of-life procedures.

### 3.2.4 Skills in end-of-life care

Variation in confidence performing specific palliative skills among the GPs was found (Figure 3.1). The task that most GPs felt least confident about was medical treatment in the terminal phase (56-59%) (i.e. use of 'just-in-case box' and administration of medicine subcutaneously). The skills that most GPs had confidence in were treatment of nausea, obstipation, and pain (88-90%).



Figure 3.1. Percentage of GPs who reported that they felt confident/very confident about taking care of nine different elements of end-of-life care. (N=571 GPs).



### 3.2.5 GPs characteristics and the provision

The GPs characteristics were only intermittently associated with end-of-life care, and the associations identified were scattered, with no overall pattern of associations. A higher proportion of the oldest GPs reported to be confident as key worker, but they did not report higher confidence regarding end-of-life skills. The only skill that had significant associations with GP characteristics was the subcutaneous administration of medicine, where female GPs and GPs working in rural areas felt significantly more confident than male GPs and GPs working in urban areas, respectively.

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## 3.3. PAPER III

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### 3.3.1 Phase 0: Identification of barriers and facilitators

The two main barriers to end-of-life care among GPs identified after the literature search were lack of identification of patients in the end-of-life phase, especially patients with non-malignant diseases [91], and variations in skills and knowledge among GPs concerning end-of-life care [57-59].

The facilitators which could amplify the effect of the intervention were identified to be: case-based teaching [23], guidance rather than orders [43], educational meetings in small groups [13], engaging with peers [13, 23, 43, 44], active participation [13, 23, 43, 44], sharing experiences among peers with end-of-life care [13, 23, 43, 44], involving opinion leaders [13], encounters with specialist [13, 43].

### 3.3.2 Phase 1: Modelling of intervention

The intervention consisted of two components: a CME session and an EDS. The content of the CME session was based on the identified barriers in phase 0 and an updated national guideline on palliative care for general practice published by the Danish College of General Practitioners [79]. The content of the CME session is listed in Table 3.5 and in the script in appendix 2.

The pop-up window appeared in the electronic patient record (Figure 3.2) and had four functions: an identifier of the patient's potential end-of-life needs (through the triggers), a reminder to the GP of the patients and actions to take (the GP could decide when the pop-up window should be triggered next), medical advice (symptom-based recommendations integrated with the existing medical prescriptions), and finally three checklists of palliative tasks to consider at some time point when the patient is in the end-of-life phase.

*Table 3.5. Programme and content of the CME meeting about palliative care*

<b>Time</b>	<b>Curriculum covered in each session</b>
<b>4.30–5.10 pm</b>	<p><b>What is palliative care?</b></p> <ul style="list-style-type: none"> <li>- Definition and changes in the understanding of palliative care. Focus on end-of-life care</li> <li>- Disease trajectories and the challenges in identifying when end-of-life care is needed</li> <li>- Discussion of patient case: (short film)</li> </ul>
<b>5.25–6.00 pm</b>	<p><b>What are the patients' palliative needs?</b></p> <ul style="list-style-type: none"> <li>- Results from a Danish survey among palliative patients</li> <li>- Discussion of two patient cases (short films)</li> </ul>
<b>6.30–6.45 pm</b>	<b>Presentation of the local palliative team by the palliative physician</b>
<b>6.45–7.35 pm</b>	<p><b>Medical skills and practicalities</b></p> <ul style="list-style-type: none"> <li>- Prescription of just-in-case<sup>1</sup> box, terminal declaration<sup>2</sup>, use of EDS, etc.</li> </ul>
<b>7.45–8.00 pm</b>	<p><b>Local support to patients and relatives</b></p> <ul style="list-style-type: none"> <li>- Which alternatives does the GP have? Who else can help and support?</li> </ul>

Figure 3.2. The EDS pop-up window generated in the medical records to be filled in by GP.

Palliative care

CPR-number: XXXXXX-XXXX

**Verified diagnosis**

Date:

Show diagnosis

**Contact to hospital**

Outpatient at hospital?\*

Yes  No

Has the patient "free" admission to hospital?\*

Yes  No

Where?

**Contact in practice\***

Staff:

GP:

**Pop-up irrelevant**

Why?:

Comments:

**Needs assessment**

EORTC<sup>1</sup>

**Performance**

Performance status<sup>2</sup>

**Should be triggered next time**

Presence of patient

Without presence of patient

**Administrative tasks**

Applied for terminal declaration\*

Prescribed just-in-case box\*

Applied for drug reimbursement\*

Established out-of-hours contact

**Other tasks**

Medicine revision  Legal issues

Talked about psychological issues  Talked about leave for relatives

Talked about dietary supplement

**Established contact to**

Relatives  Palliative specialists  Nursing home

Priest  Community nurse  Hospice

**Check list**

Yes  No

Administrative tasks

Other tasks

Established contact to

**Type of contact**

Letter (mail)  Consultation in practice

Email  Home visit

Text messages

**Hyperlinks**

Symptom-based recommendations

Palliative list

1: Directly linked to the EORTC QLQ-C15-PAL [92] in the palliative guideline [79] : ready to print and hand out to the patient.

2: ECOG Performance Status [93].

\* The information is automatically transferred to the palliative list.

The following triggers in the electronic patient record were chosen to identify patients with an end-of-life with life expectancy of 12 months or less: diagnosis of malignancy, palliative diagnosis or COPD with either MRC dyspnoea scale=5 [94], body mass index <18 or FEV1 <30 (see the appendix in Paper III for exact list of diagnosis).

The other part of the EDS was the list showing all patients in end-of-life identified by the GP (Figure 3.3).

Figure 3.3. The list showing all patients with palliative needs in the practice. One tab is for patients with cancer, one for patients with COPD. The tab for COPD contains additional information on smoking status, number of exacerbations within the last year, and MRC breathlessness score.

Cancer patients													Patients with COPD			
Name	CPR-number	Age	Diagnosis	Term. decl.	Perf. status	C diag	P diag	Cancer diagnosis	GP	Staff	Specialist care	Latest pop-up	Next pop-up	Last consultation		
Steen Lauritsen	160833-xxxx	80	C34		4	●		19/3/2012	cl	mga	●	7/2/2014 *	20/2/2014	7/2/2014		
Annette Bach	30726-xxxx	87	C34	●	3	●	●	6/1/2013	cl	bh		3/1/2014 *		3/1/2014		
Frank Thygesen	030539-xxxx	74	C18		2			28/11/2013	tg	mga		28/11/2013		18/2/2014		
Mathias Jensen	040767-xxxx	46	C25		2		●	9/4/2013	cl	bhl	●	31/1/2014	5/3/2014	31/1/2014		
Hanne Petersen	300248-xxxx	66	C50				●	3/5/2013	tg	mga		15/1/2014		15/1/2014		
Ole Madsen	120955-xxxx	58	C61			●		7/9/2010	cl					19/11/2013		
Peter Hansen	180538-xxxx	75	C20			●		28/11/2013						5/12/2013		
Lone Petersen	160731-xxxx	82	C50			●		17/1/2012						22/8/2013		
Henrik Nielsen	200337-xxxx	76	C91					23/8/2009						18/7/2013		

All names and information on the list are made up.

The information about key elements was automatically retrieved from data in the pop-up window and existing information in the electronic patient record. The list had two tabs to allow different headings for cancer and COPD patients. The main purpose of the list was to provide the GP with an overview of the population of patients with palliative needs.

### 3.3.3 Phase 2: Pilot testing of intervention

The evaluation of the pilot testing of the intervention was done separately for the CME session and the EDS. The process evaluation focused on the fidelity of the intervention (adherence to blueprint and the reach), the quality, the impact, and the factors in the context that could have influenced the outcome of the intervention.

#### The fidelity:

Adherence to blueprint.

The CME sessions had high adherence to the blueprint, which was developed and implemented as intended. The EDS was developed, although delayed, and integrated into the electronic patient record as intended. But the EDS was shut down shortly after the implementation due to external legal issues that concerned data collection from GPs in Denmark in general. Hence, the functionality showed high adherence to the blueprint, but the implementation had low adherence.

The reach.

In total, 14.2% (120 GPs) of the invited GPs attended one of the six CME sessions and 5.9% (50 GPs) signed up for the EDS. The overall reach of the intervention was low, which compromises the fidelity.

#### Quality of CME session

In total, 115 (95%) participants answered the questionnaire about the quality of the CME session. There was high correspondence between the answers in the questionnaire and the statements in

the interviews. The participants reported that they had gained new knowledge, useful tools, and benefited from participating. Some areas in end-of-life context emerged as new to most of the GPs. These areas included a broader and newer understanding of end-of-life care, including the need to provide care to patient groups other than cancer patients, the benefits of assuming a proactive role, and organising the care, and an increased awareness of patients with potential palliative needs.

Hence, the CME session succeeded in addressing the main barriers.

#### Impact of CME session

In the three-month evaluation 29 (25%) GPs participated. They stated that they have had an increased awareness about palliative needs in patients with non-malignancies and had adapted a more proactive approach. However, 10% stated they had not had any patients with palliative needs in their practices during the time after the CME session and until the questionnaire was received.

#### Impact of EDS

It was impossible to evaluate the impact of the EDS due to the early shutdown.

#### The context of the intervention

A time-specific event, which could have affected the context, was a nationwide disagreement between the GPs and Danish Regions, concerning the contract between the GPs and the public funding authorities (the Danish Regions). This could have made some GPs reluctant to attend the CME session as the regional administration, i.e. the Central Denmark Region, was involved in the CME session. Hence, this might have hampered the effect of the intervention.

# **CHAPTER 4:**

## **DISCUSSION OF METHODS**

This chapter addresses the strengths and weaknesses of chosen designs and methods in the three papers.

The focus will be on essential methodological issues for each paper cognizant of the fact that there are more issues to discuss than the highlighted ones. Papers I and II are both observational epidemiological studies. The primary points of discussion of methods in these two papers concern bias and validity. Hence, these key issues will be explained and illustrated using examples from the two papers. Then the design of Paper III will be discussed highlighting methodological concerns from the different phases of the development of the intervention. At the end of the chapter, the external validity of all three papers will be discussed.

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## 4.1 PAPERS I AND II

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Paper I is a retrospective register-based study. The design of Paper I was a mix of a cohort and an ecological study, and hence the design could be called ‘register-based cohort study with an ecological exposure’. The study design has components from both an ecological study and a cohort study. The ecological element is the exposure (propensity to pay home visits) on the population level based on data from all patients listed at a general practice. In ecological studies exposures are compared either over time or between different areas [95]. If we had chosen a purely ecological design to investigate the association, we could have compared proportion of home deaths in different geographical areas. However, it would have underestimated the previously identified variation between practices within an area [96]. If the association was investigated over time, there would have been a risk of confounding due to an overall decline in home visits paid by GPs throughout Europe during the last decades [97]. By combining the cohort study and the ecological study, we bypassed these issues.

The outcomes (dying out of hospital and bed-days in hospitals) were calculated on the patient level, which imitates a cohort study. The mix of designs in Paper I reduced the risk of confounding by indication (i.e. that the GPs would pay home visits to patients because they knew the patient had a preference for dying at home (out of hospital/hospice)) that could be present in a cohort study (see section 4.1.2.3 on confounding, page 49).

The design of Paper I exploited the variation in propensity to pay home visits to create a *natural experiment*, i.e. a cohort study, which imitates an experiment [95]. The underlying assumption in Paper I was that patients’ choice of GP was independent of the GP’s propensity to pay home visits. This seemed plausible, as there was no public information about either number or rates of home visits paid by GPs. The design made it possible to investigate an association that was otherwise difficult to investigate. To conduct the corresponding experiment would be practically challenging and have an inherent risks of introducing bias due the observer effect and self-selection of participants.

Paper II is a cross-sectional study where information refers to the same point in time. It provides an overview of the prevalence at a given time of the chosen outcomes [95]. The cross-sectional study can be used to investigate associations between factors and outcomes but cannot imply causality. This makes the cross-sectional design suitable for determining the GPs’ confidence and skills in the provision of end-of-life care.

### 4.1.2 Bias

There are two different kinds of bias which are important to address in Papers I and II: selection and information bias.

#### 4.1.2.1 Selection bias

Selection bias is systematic errors in studies created by the way groups are selected or if a factor is likely to influence the groups in different ways. A bias will be created if the outcome is unevenly distributed between the groups compared [95].

A general strength in Papers I and II was the use of valid national and regional registers in the inclusion of study populations, which reduced the risk of selection bias.

In Paper I, all Danish citizens in 2003 above 40 years of age (or when turning 40) from 2003-2011 listed at a general practice were included based on the unique identification number. This diminished the risk of selection bias as data were available on every citizen and no consent from the participants was needed.

The most pronounced risk of selection bias was in Paper II due to self-selection. All the GPs in Central Denmark Region were invited to participate in the questionnaire survey. Maximising the response rate was an important aspect of reducing the selection bias to get valid results in the cross-sectional study. In this study several things were done to enhance the response rate:

- Retrieving all GP characteristics from registers rather than from the questionnaire shortened the questionnaire and increased the validity of the data.
- A reminder was sent to all the non-responding GPs after three weeks
- Responders were reimbursed a standard rate 122 DDK (€16) for the time spent on the questionnaire.
- A pre-stamped envelope was enclosed with the questionnaire.
- Answers to the questionnaires were anonymised (but registered with a serial number).

It was possible to compare responders to non-responders to estimate the magnitude of the eventual selection bias due to available register-data on GP characteristics (age, gender, organisation of practice, geographical area). The responders were slightly but significantly younger, and there was a higher proportion of female GPs compared with all GPs in the region. Whether or not this self-selection has created a bias depends on whether gender and age are associated with the outcomes, and hence create an uneven distribution.

The pattern of non-responders being older is a pattern found in other survey studies [98, 99]. It is difficult to estimate how and whether the results will be biased. On one hand, older GPs were found to be more confident and have greater interest in the provision of end-of-life care [34], and therefore this confidence would be underestimated in Paper II. On the other hand, non-responders often find the topic of questionnaires less salience than the responders [100, 101]. This would result in an overestimation of the associations if the participants were more engaged in the topic than non-participants. Whether or not these opposing trends counterbalance each other is impossible to say, hence estimation of the direction of bias is impossible. This implies that generalisation from the survey should be interpreted with caution.

#### 4.1.2.2 Information bias

Information bias, or misclassification, is bias that arises from errors in measurement of exposure, outcome, or confounding that result in different quality of information. Information bias can be either differential or non-differential depending on whether the misclassification is related to other variables or not [95].



The risk of information bias was reduced in Papers I and II by the use of valid national and regional register-based data. The data in the registers were collected for other purposes and hence unrelated to the aim of the papers. Furthermore, linkage between the registers using either the personal identification number or the general practice provider number allowed checking the completeness of the data.

The most pronounced problem with information bias was in Paper I. In Paper I, this problem was associated with the outcome 'place of death' as the registration of place of death could be subject to differential misclassification.

*Table 4.1 showing the place of death in percentages (%) of all deceased persons (n) per year for the time span 2004-2012. Calculated from data of the Register of Causes of Deaths.*

	2004	2005	2006	2007	2008	2009	2010	2011	2012
Hospital/hospice	47.7	47.9	47.9	46.5	46.6	48.7	45.7	45.4	45.5
Residence*	42.8	42.8	42.8	30.3	28.8	37.2	26.0	26.5	26.8
Known address	1.1	1.1	1.2	4.1	4.6	5.3	4.6	4.6	4.7
Unknown address	1.0	1.1	0.7	0.6	0.7	0.6	0.6	0.6	0.5
Missing	7.3	7.1	7.3	18.5	19.4	8.6	23.1	23.0	22.4
Deceased persons	54,076	53,293	53,842	54,369	53,410	53,723	53,526	51,597	51,188

*\*Residence as place of death includes home and nursing homes.*

Throughout the time span, there was little variation in the proportion of patients dying on hospitals (Table 4.1.). In contrast, the proportion of missing values in place of death increased while the proportion of home deaths decreased considerably from 2007 and onwards. In 2007, it became mandatory to use an electronic version of the death certificate. However, the paper version was still used. Money was granted to the Register for Causes of Deaths in 2009 to manually register place of death from the paper version of death certificates. This explains the low proportion of missing values in 2009. The distribution of place of death in 2009 was similar to the distribution in 2004-2006. It could indicate that home deaths were under-reported after 2007, since the proportion decreases after the introduction of the electronic death certificate. This supports the suggestions that the rise in missing values and the fall in the proportion of home death from 2007 and onwards could be related [21].

If the missing registration of place of deaths were related to the GPs propensity to pay home visits, it could cause differential misclassification, which would bias the results. It is impossible to say if a possible differential misclassification would over- or underestimate the association found between propensity to pay home visits and home deaths.

To account for this, we used the outcome 'dying out of hospital/hospice'. The proportion registered as death in hospital was stable throughout the period, unaffected by the introduction of the electronic deaths certificate. The procedure for registration of death is assumed to be more reliable in hospital than out of hospital, which made these data more reliable. Hence, we considered death out of hospital/hospices a better proxy for home death than the actual data on home death in this paper.

The data did not allow a separation of death in hospital and hospice, which could be problematic in terms of patients' preferences for place of death. As described in the introduction, most patients prefer hospice over hospital as place of deaths (Introduction, section 1.1.2 page 16 ). However, as we estimated how the GPs' propensity to pay home visits was associated with the patients' possibility for not dying in hospital/hospice, this was less important. Another concern was the change in registration of death in hospice. Before 2007, it was registered as a home death and

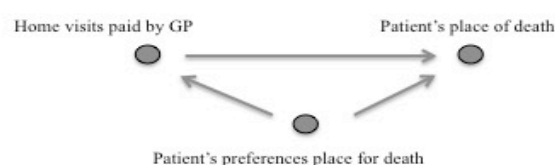
from 2007 and onwards it was registered as death in hospital. This could underestimate a possible association.

#### 4.1.2.3 Confounding

A confounder is most simply defined as “confusion of effect” [95]. The effect between the outcome and the exposure is being confused with a third variable, associated with both the outcome and the exposure.

It can be illustrated with an example from Paper I shown in Figure 4.1.

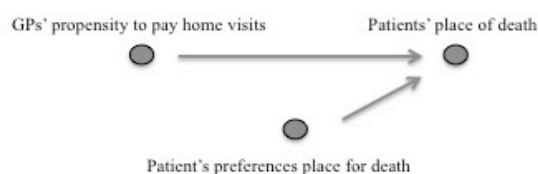
Figure 4.1 Illustration of the potential confounding effect of a known patient preference on the association between home visits and the patient’s possibility for dying at home.



If Paper I had been a cohort study, with all data collected on the individual level, there would be an inherent risk for confounding by indication: if the GP knew the patient had a preference for a home death, he/she could be more likely to pay home visits to the patient to fulfil the patient’s preference. Since the patient’s preference for a death out of hospital would also be associated with the actual place of death, it would be a confounder.

The reason why the patient’s preference was not a confounder in Paper I is illustrated in Figure 4.2.

Figure 4.2. Illustration of how patient’s preference is not a confounder in the association between GPs’ propensity to pay home visits and place of death when home visits is estimated in an ecological study.



An individual patient’s preference to die at home cannot have an impact on the GP’s general propensity to pay home visits. Hence, the preference was only associated with the patient dying at home and hence, it cannot be a confounder. We used the propensity to pay home visits from the preceding year as exposure for the cancer patients dying in the subsequent year to further minimise the risk that a dying patient’s preference for home death would have an impact on the GPs propensity that year. As illustrated above, confounding can be reduced by study design (as in Paper I), by randomisation, and finally in the statistical analyses.

In Paper I, we did not succeed fully in eliminating all confounding, as there could residual confounding left, and this especially concerned the degree of urbanisation. The degree of urbanisation was the only parameter where the composition of the practice populations was not comparable and the risk of interaction could be important.

#### 4.1.2.4 Validity

In Paper II, there is another methodological concern related to the validity of the questionnaire.

The face validity, which is the apparent understanding of the questionnaire, was tested in the pilot study. When non-validated questionnaire is used, there is an increased risk of impaired content validity. The content validity was not tested, which is the main concern in Paper II. An overall lack of clear definitions and understandings of palliative care, end-of-life care, and terminal care (see Introduction, section 1.1, page 14) adds to the concerns. Likewise, the term “key worker” is ambiguous, and tasks and expectations of a key worker are not well defined in a Danish context [53, 54]<sup>1</sup>. However, a study carried out by Brogaard et al. has shown that patients, their relatives, and GPs are able to identify the person who in their opinion had functioned as key worker and who was considered to be the ideal key worker in the disease trajectory [54]. Another Danish study investigated how GPs interpreted the term key worker [102]. Three different understandings of the function of a key worker became apparent in the paper: one was that a key worker function was related to medical tasks and diagnoses, another that the function was related to paying attention to the patient and their relatives, and the last was an understanding of the function of a key worker meant paying special attention to “the vulnerable patients” and the social aspects of diseases [102].

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## 4.2 PAPER III

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Paper III is the development of a complex intervention. An intervention can be seen as a specified 'treatment' or 'method' that is intended to modify the dependent variable(s) [103]. An intervention in general practice has several points of action and should be considered a complex intervention [81]. The design of a complex intervention allows components of the intervention to interact, various outcomes, and addresses different organisational levels [81].

The intervention was systematically developed using the complex intervention in accordance with the MRC guideline [78]. The intervention was complex as it targeted different levels, both the individual and the practice level, used different components (CME session and EDS), and had several outcomes [78]. The use of a guideline ensured systematic development and explicit reporting. This improved the applicability of the tailored interventions to other settings as it is possible to adapt or modify relevant components depending on the actual setting.

In the following, one element of the methods from each of the phases will be underlined and discussed.

### 4.2.1 Phase 0

We used three different methods to identify and apply the evidence-base to a Danish context: narrative literature search, interviews with “experts”, and experience within the research group. This part will focus on the narrative literature search and how its strength and limitation could potentially have an impact on the paper.

Narrative searches can be used to present a general overview of a topic [104]. Our search was driven by a general need for information and not by a stated question. The evidence in the area of palliative interventions in general practice was limited, so by performing a narrative search, we

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<sup>1</sup> In Danish traditionally “tovholder” but in a more present term “gennemgående sundhedsperson”

were able to use evidence from other similar settings. If we had chosen a systematic search, we could have lost valuable information due to search restrictions.

The drawback of using the narrative search compared with the systematic is that you cannot be sure whether the search is exhaustive. Hence, you might lose important information. Another risk is presenting biased results due to the exclusive inclusion of studies showing effect. However, this was not a concern in the Paper as the aim of the search was to provide a basis of evidence. Hence, a narrative search was more appropriate despite the lower level of confidence compared with a systematic search.

#### 4.2.2 Phase 1

In the development of both components, we included stakeholders to increase the applicability and acceptance of the intervention. In both cases, we used existing organisations and ways of communicating with the GPs.

We could have improved our collaboration with stakeholders if we had made a systematic analysis of potential stakeholder, which might have included other persons and organisations [66]. However, it was out of the scope in this study. A disadvantage of the inclusion of these stakeholders could be if they had an agenda that deviated from the aim of the study. A challenge when using existing organisations and ways of communicating is that they may not be in line with best practice and you might have to compromise. However, in our study the inclusion of the stakeholder outweighed the disadvantages.

#### 4.2.3 Phase 2

A process evaluation is a way to get insight into the contribution of different components in a complex intervention [66]. We used process evaluation to evaluate the pilot testing of the intervention. Process evaluation in a pilot study has the advantages of providing information about the feasibility of the study and optimising its design [77].

Unfortunately, we were only able to evaluate the CME session fully and not the EDS at all, and hence not the intervention as a whole due to the untimely shut down of the EDS.

The *reach* of the CME session can be used as to illustrate why it is important to break an evaluation into pieces. The attendance rate to the CME session was 14.2%, which was low in a Danish context. The low attendance rate in this study could have several explanations: lack of interest in the topic, no need for education in palliative care, timing of the intervention, or a poor dissemination of the invitation to the CME session. However, in our design the evaluation did not allow us to cast light on the reasons for the low reach, hence we could only conjecture. Lack of proper evaluation of the reach is a limitation, since it is not possible after the pilot testing to optimise and adjust the design in order to increase the attendance rate.

The reach of an intervention could be an important part of feasibility, which we had not clearly defined. The lack of a defined feasibility was another limitation.

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## 4.3 GENERALISABILITY

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The question of generalisability considers whether results from the study population are valid in other populations [95].

### 4.3.1 Paper I

In the light of the discussion of bias in Paper I, we believe that our results are valid and generalisable to other countries in which GPs are responsible for the at-home care treatment. However, careful consideration of possible differences in culture and health care is always required before extrapolating the results to other countries that deviate considerably from Denmark.

### 4.3.2 Paper II

As discussed above, selection bias has occurred in our study due to self-selection, which impairs the generalisability of Paper II. However, as age and gender of GPs are only associated with two aspects of end-of-life care (i.e. confidence being a key worker and administering medicine subcutaneously) and not found to define a specific subgroup of GPs in the provision of end-of-life care, generalisation should be made with this in mind. The Central Denmark Region comprises both rural and urban areas; thus, the GPs here can be considered as being representative for all Danish GPs. Just as in Paper I, consideration is required when the results are extrapolated to other cultures and countries.

### 4.3.3 Paper III

Complex interventions function best when tailored to a specific setting and to specific participants [81]. This may be at the expense of the generalisability of the approach used. However, the detailed reporting of the development and process evaluation makes it easier to apply those parts that are applicable to another setting. Overall, the findings from this intervention can be generalised to other areas of Denmark and countries with a similar culture and health care system.

# **CHAPTER 5:**

## **DISCUSSION OF RESULTS**

The following chapter will discuss highlights of the results from the three papers in the dissertation.

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## 5.1 PAPER I

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This is the first study to our knowledge that examines the association between GPs' propensity to pay home visits and place of death for cancer patients in a large national cohort without the risk of the result being biased by confounding by indication. We found a dose-response association between the GPs propensity to pay home visits and their patients' likelihood of both spending less time at hospital during the last three months of life and of a death out of hospital. Other studies have identified similar associations between home visits and place of death [29, 31, 38]. However, these previous studies focused on the patient level, hence were subjected to confounding by indication.

The finding that the GPs' propensity to pay home visits was associated with amount of hospitalisation during the end-of-life period could be used as a proxy for place of care. Kronman et al. found the same association but used home visits on the patient level. The finding is important as place of care is another important element in a successful palliative pathway different from place of death [105]. The GPs' propensity seemed to be more strongly associated with the likelihood of being three days or less in hospital than 20 days or more in hospital, OR 1.11 and 0.95, respectively, when groups 1 and 4 are compared. This could indicate that when patients are hospitalised for longer periods, the actions of the GPs are less important. To be able to explore this fully, the number of hospital admissions should be combined with bed-days in an analysis. It draws attention to the potential importance of GPs' home visits in preventable hospitalisation at the end of life. Kronman et al. found that home visits on the patient level were positively associated with less preventable hospitalisation for patients with COPD and heart failure and an overall reduction of health care costs [38].

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## 5.2 PAPER II

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The GPs have an important role in end-of-life care. Especially patients with non-malignancies are dependent on GPs because 96% of the patients that received specialised palliative care in Denmark in 2013 were cancer patients [106].

Hence, we investigated how GPs reported provision of palliative care to patients with non-malignancies. The GPs reported that they provided end-of-life care to cancer patients twice as often as to patients with non-malignancies. This disparity in end-of-life care between different patient groups is consistent with findings in other studies [43, 48]. However, to our knowledge this paper is the first to report this from the GPs' perspective. Since there is no registration of basic palliative care, this is the best estimate of the difference in provision of end-of-life care to different patient groups in general practice.

We found that if a GP "often" or "always" provides end-of-life care to one group of patients with one kind of non-malignancies, they were more likely to do the same to another group of patients with non-malignancies. The same consistency was not found when end-of-life care to cancer patients was compared with that given to any other of the other patient groups. This suggests that providing end-of-life care to patients with non-malignancy could reflect an approach to end-of-life care based on needs rather than diagnoses, or a broader and newer understanding of end-of-life care (see Introduction, section 1.1, page 14). The term 'palliative care', which was used in the questionnaire, has traditionally been linked to terminal care of cancer patients. This may make the GPs more likely to agree to the provision of end-of-life care to cancer patients than to patients with non-malignancies. Hence, the possible limitation in content validity in the questionnaire limits the interpretation of the results. However, regardless of whether the finding fully reflects differences in awareness of who would benefit from end-of-life care or whether there are other

reasons for this difference, it still reveals an increased focus from the GPs on cancer patients compared with patients suffering from non-malignancies.

We found that 76% of GPs reported feeling “confident” or “very confident” about being a key worker in the palliative trajectories. This is an increase compared with a previous Danish study from the Capital Region of Denmark, where 57% felt confident about being key worker [58]. The increase in proportion of GPs feeling confident could be due to a general increased focus on palliative care in Denmark over the last years [107]. The increase in confidence could also be subjected to geographical variation. However, we did not find the degree of urbanisation to be associated with confidence in being a key worker in our study, which was performed in a region with both urban and rural areas. However, a report from 2012 showed variation in the proportion of home deaths throughout the five regions in Denmark [21]. Home was the place of death for 29% of all deceased between the years 2007-2011 in Denmark. In the Capital Region of Denmark, the percentage dying at home was 23%, whereas it was 35% in the Central Denmark Region.

The two results discussed above illustrate that the majority of GPs were aware of cancer patients’ palliative needs and felt confident about taking part in the palliative trajectory. However, there were still approximately 25% of the GPs that did not offer palliative care to cancer patients or lacked confidence in being key workers in palliative trajectories, and, as mentioned, these figures were even greater when it came to providing end-of-life care to non-cancer patients. Hence, there is a need to draw attention to end-of-life care in general practice and find ways to support and educate the GPs.

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### 5.3 PAPER III

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In gathering the evidence-base in phase 0, we found that lack of identification of patients in the end-of-life phase, especially patients with non-malignancies, was a well-known barrier to provision of end-of-life care [42, 43, 108]. Hence, we wanted the intervention to facilitate the identification and awareness of patients with non-malignancies with possible end-of-life needs.

This discussion of results will focus on GPs’ identification of patients in the development of the intervention and the pilot testing.

In phase 1, the development of the two components (the CME session and the EDS) in the intervention, integrated the question about lack of identification in different ways. As discussed in the introduction the term palliative care is ambiguous [8]. Hence, there was a need to define the term prerequisite to increase knowledge about whom to identify as having palliative needs. The different challenges in the identification with relation to different disease trajectories were discussed in the CME session by the GPs [48] and the surprise question “would you be surprised if this patient were to die in the next 6 to 12 months?” was introduced as one among other tools [109].

In the EDS, an identifier was integrated, making the primary identification automatic. However, identification independent of the GPs awareness does not necessarily lead to increased end-of-life care. Mason et al. made a similar computerised tool to identify patients with palliative needs. They found that some GPs had resistance to registering the identified patients as ‘palliative’ due to its association to death [73]. This illustrates the importance for breaking down barriers and



changing attitudes towards end-of-life care in order to improve the identification and awareness of patients with end-of-life needs.

In phase 2 the pilot testing of the CME session showed an increased awareness about the palliative needs in patients with non-malignancies. However, in the three-month evaluation, 10% stated they had not encountered any patients with palliative needs since the CME session. GPs has on average 14 patients dying every year (estimated) of which a third die of cancer [64]. Hence, one may speculate whether this indicates a lack of change in their understanding of end-of-life care and awareness of patients with palliative needs. Previous research showed that a change in self-confidence in GPs after attending CME session is not necessarily followed by a change in patient care [72]. Hence, it is important to include patient-related outcomes in future evaluations of interventions like ours.

# **CHAPTER 6:**

## **CONCLUSIONS**

This chapter presents the main conclusions to the research questions based on findings in the three papers.

The overall aim of the dissertation was to investigate different aspects of end-of-life care in general practices.

The first research question focused on home visits paid by the GPs and whether home visits to cancer patients were associated with place of care at the end of life and place of death.

In Paper I, we showed that the GPs' general propensity to pay home visits to adults was positively associated with their cancer patients having fewer days of hospitalisation at the end of life and their likelihood of dying out of hospital in a dose-response-like association.

Hence, we can conclude that home visits paid by the GPs appear to have an important role in provision of good end-of-life care. This is an important observation, as other studies have shown that the rate of home visits performed by the GPs has been decreasing over several years.

The second research question focused on areas where the GPs needed support in order to optimise the end-of-life care, and how support for GPs in end-of-life care could be developed and implemented.

Based on a questionnaire study among GPs in Central Region, Denmark, we found in Paper II that overall, the majority of GPs felt confident in the provision of end-of-life care; however, we also found the GPs to be a diverse group of providers of end-of-life care, where confidence in one issues was not consistently associated with confidences in other related aspects of end-of-life care. Medical treatment in the terminal phase was the skill with the lowest percentage of confident GPs.

We further identified a discrepancy in the provision of end-of-life care to different patient groups, as the GPs were twice as likely to offer end-of-life care to their cancer patients as to patients with non-malignancies, and even cancer patients were not always offered end-of-life care. Hence, there is a need to support the GPs in realising the importance of end-of-life care and especially with regard to patients suffering from non-malignancies. Only a minority of the GPs reported that they organised their end-of-life care. Finally, the majority of GPs felt confident about being key workers in end-of-life trajectories. However, the confidence was inconsistently associated with carrying out key worker tasks.

These findings led to the following conclusions: the GPs constitute an inhomogeneous group, both concerning their self-perceived skills and confidence in providing end-of-life care. The study shows that it would be of importance to clarify the content of the key worker role, as prior studies have shown the importance of someone taking the responsibility for the coordination and planning of end-of-life care. Furthermore, the results showing lack of organisation concerning end-of-life care underline the importance of not only focusing attention on medical skills but also on how care is organised by the GP.

On the basis of these findings, future interventions should aim at covering a variety of issues at the same time, especially focusing on patients with non-malignancies and the ensuring of optimal medical treatment in the terminal phase.

Such interventions could be continuing medical education and electronic decision support.

In Paper III, we described a systematic way to develop and implement an intervention to support the GPs in end-of-life care consisting of a CME session and an EDS. The development and pilot testing was based on a guideline on complex intervention by the MRC. The pilot test indicated an overall appreciation by attending GPs of the CME sessions that addressed identified areas that needed support. The EDS was fully developed and integrated into existing medical records.

To conclude, it is possible to support the GPs in the provision of end-of-life care. A CME session is a way to address identified barriers to end-of-life care and change the understanding of end-of-life care in general practice. Concerning the EDS, we can conclude that it is possible to design a

functioning decision support system for end-of-life care that is integrated into already existing technology. However, it still remains uncertain whether a combination of CME session and EDS has an impact on the provision of end-of-life care.

To sum up, the dissertation has shown that the GPs are important in end-of-life care and that they overall feel confident providing it, despite variations in their skills to provide end-of-life care. Hence, there is a need for initiatives to increase and optimise the end-of-life care already provided to ensure more patients will be able to be spent their end of life at home and die at home in line with their end-of-life preferences.



# **CHAPTER 7:**

## **PERSPECTIVES AND FUTURE RESEARCH**

This chapter offers a perspective on aspects of end-of-care in general practice in Denmark.

In Paper I, we found a variation between general practices with regard to the propensity to pay home visits. The variation was associated with cancer patients' hospitalisation at the end of life and place of death. Hence, the GPs appear to have an important role in end-of-life care for their cancer patients.

Since our study did not allow causations, the identified association between propensity and cancer patients' end-of-life care needs to be further investigated, assessing what caused the effect identified. The home visits themselves could be causing the effect, or they could be a proxy for ways of organising care or fulfilling the role of a GPs. Hence, part of such investigations would include focusing on the reason for the variation in propensity to pay home visits between practices. Furthermore, it would be interesting to investigate whether there is a need to increase the declining home visit rate to optimise end-of-life care.

We only included cancer patients in our study, but positive associations between home visits on the patient level and preventable hospitalisation for patients suffering from non-malignancies have previously been identified. Hence, this and the association between propensity to pay home visits in general and place of death for patients with non-malignancies need further investigation in a design like that in Paper I.

The need for a key worker in palliative care trajectory has previously been identified both within the health care system and for patients and relatives. The majority of GPs in our study felt confident being such a key worker; however, they did not necessarily feel confident carrying out the tasks related to being a key worker.

Hence, there is a need to further clarify what is expected of the GPs in end-of-life trajectories.

The questionnaire in Paper 2 revealed areas which need to be optimised to ensure that patients can spend their end of life at home and get the optimal end-of-life care. Hence, there is a need to educate GPs regarding end-of-life care and further investigate how more GPs can be confident in carrying out tasks related to end-of-life care. It is important to bear in mind that GPs reported diverse confidence in related skills, and confidence was in general unrelated to GP characteristics.

One of the areas that needs extra focus is identification and awareness of patients with possible end-of-life needs. This is prerequisite for the high quality provision of end-of-life care. In Paper II, we showed a disparity regarding which patients are offered basic palliative care by general practitioners. Hence, there is a need to find ways to make the provision of end-of-life care dependent on needs rather than diagnoses.

The identifier function as a part of the EDS in the intervention was one way of helping the GPs.

The complex intervention was developed and implemented. The results from the pilot testing showed that the CME session succeeded in addressing identified barriers like lack of identification. However, it remains uncertain whether the CME session had an impact on clinical care. It has previously been found that attendance to CME sessions does not necessarily cause change in clinical care despite reports of a change in attitude and confidence in GPs. Hence, there is a need to further assess the effect of the CME session on patient-related outcomes. Whether or not combining the CME session and the EDS proves to be useful remains uncertain. However, the EDS needs to be evaluated in itself with regard to functionality and acceptability prior to a full-scale intervention using patient-related outcomes.

Furthermore, it could be beneficial to assess the implementation itself, as the participation rate was low in the set-up tested in this study.

# **CHAPTER 8:**

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# **CHAPTER 9:**

## **SUMMARIES**

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## ENGLISH SUMMARY

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Summary of the dissertation: Provision of end-of-life care in general practice

Most patients prefer to stay home in the last phase of life and die at home. However, in Denmark the majority die on hospital. General practitioners have the responsibility for the at-home care and are pivotal in fulfilling the patients' end-of-life preferences. Hence, it is natural to focus on the GPs' role and confidence in the provision of end of life care.

### **Aim**

The overall aim of the dissertation was to answer two research questions

Research question A:

Are home visits paid by GPs associated with their cancer patients' place of end-of-life care and place of death?

Research question B:

In which issues do Danish GPs need support in the provision of end-of-life care? Is it possible to develop an intervention that supports GPs' in the provision of end-of-life care?

These research questions were investigated in three papers with the following aims:

### Paper I

The aim was to assess the association between the GPs' propensities to pay home visits in general and their cancer patients' likelihood of avoiding hospitalisation the last three months of life and for dying out of hospital.

### Paper II

The aim of this study was to assess to what degree GPs report providing end-of-life care with regard to patients with different diseases, their confidence with being a key worker, their organisation of end-of-life care, and their medical and psychosocial end-of-life care skills. Furthermore, we aimed to analyse whether specific characteristics of the GPs and their practices were associated with their perceived abilities to provide end-of-life care

### Paper III

The aim of this study was to develop and pilot-test an intervention consisting of a Continuing medical education session and electronic decision support to support the end-of-life care in general practice for patients with cancer or chronic obstructive pulmonary disease.

### **Methods**

Paper I was a national register-based cohort study with an ecological exposure. Paper II was a questionnaire survey in Central region Denmark among GPs, examining their confidences and skills in providing end-of-life care. Paper III was the development of a complex intervention to

support GPs in the provision of end-of-life care. The development was based on guidelines from the British Medical Research Council on complex interventions.

### **Results**

In Paper I, we found the GPs' propensity to pay home visits was positively associated with their cancer patients' likelihood of avoiding hospitalisation the last three months of life and die on hospital. In Paper 2, we found that GPs were more likely to offer end-of-life care to patients with cancer than to patients with non-malignancies. Most GPs felt confident about being key workers in palliative trajectories. The GPs' confidence in end-of-life skills varied, and it was not the same GPs who felt confident in the different areas. Hence, the GPs were a diverse group. In Paper III, a complex intervention was developed consisting of a continuing medical education (CME) session and an electronic decision support system (EDS). Both components were developed by working groups comprising stakeholders. In the pilot testing, 14% of the GPs in the region attended the session and 5% signed up to use the decision support.

### **Conclusion**

This dissertation shows that GPs are important in end-of-life phase of their patients. Overall, they feel confident about providing end-of-life care despite variations in their end-of-life skills and ability to perform end-of-life tasks. Hence, there is a need for initiatives to increase and optimise the end-of-life care already provided to ensure more patients will be able to be spent their end of life at home and die at home in line with their end-of-life preferences.

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## DANSK RESUME

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Dansk resume af ph.d.-afhandlingen med den danske titel:

Praktiserende læger og palliation i den sidste del af livet

### **Baggrund**

De fleste mennesker ønsker at tilbringe deres sidste tid og dø i eget hjem. Men i Danmark dør de fleste på hospital. Praktiserende læger er ansvarlige for behandling i hjemmet. Det giver dem en vigtig rolle i forhold til at opfylde patienternes ønsker for den sidste tid. Det er derfor naturligt at fokusere på praktiserende lægers rolle i den sidste del af livet – det palliative forløb.

### **Formål**

Det overordnede formål for ph.d.-afhandlingen var at belyse to spørgsmål:

Forskningsspørgsmål A:

Er hjemmebesøg foretaget af praktiserende læger associeret med, hvor deres kræftpatienter dør?

Forskningsspørgsmål B:

På hvilke områder har praktiserende læger brug for støtte til palliativ behandling? Er det muligt at udvikle en intervention, som støtter de praktiserende læger i at give palliative behandling?

Disse to forskningsspørgsmål blev besvaret i tre forskningsartikler med følgende formål:

Artikel I:

Formålet var at undersøge associationen imellem praktiserende lægers tilbøjelighed til at tage på hjemmebesøg og deres kræftpatienters sandsynlighed for ikke at blive indlagt på hospital i de sidste tre måneder af livet eller dø på hospitalet.

Artikel II:

Formålet var at undersøge i hvor høj grad praktiserende læger rapporterede: at de tilbyder palliativ behandling til patienter med forskellige sygdomme, at de føler sig fortrolige med at være tovholder på palliative forløb, og at de organiserer både deres palliative behandling og deres medicinske og psykosociale færdigheder inden for palliativ behandling. Derudover var formålet at analysere om specifikke karakteristika ved praktiserende læger var associeret med deres egen opfattelse af egne evner til at give palliativ behandling.

Artikel III:

Formålet med studiet var at udvikle og pilot-teste en intervention, som bestod af et videreuddannelsesmøde og en elektronisk beslutningsstøtte, for at støtte den palliative behandling i almen praksis for patienter med kræft eller kronisk obstruktiv lungesygdom.

### **Metode**

Artikel 1 var et nationalt register-baseret kohorte-studie med økologisk eksponering. Artikel 2 var en spørgeskemaundersøgelse blandt praktiserende læger i Region Midtjylland om deres fortrolighed med palliativ behandling. Artikel 3 omhandlede udviklingen af en kompleks intervention, som havde til formål at støtte praktiserende læger i palliativ behandling. Interventionen blev udviklet ud fra den guideline, som det britiske forskningsråd (MRC) har udarbejdet for komplekse interventioner.

### **Resultater**

Artikel 1 viste, at praktiserende lægers tilbøjelighed til at tage på hjemmebesøg generelt var positivt associeret med deres kræftpatienters mulighed for at begrænse antallet af sengedage på hospital de sidste tre måneder af livet og at dø på hospitalet. Artikel 2 viste, at praktiserende læger oftere tilbød palliativ behandling til kræftpatienter end til patienter med andre sygdomme. De fleste læger følte sig fortrolige med at være tovholder i palliative forløb. Lægernes fortrolighed med at udføre palliativ behandling varierede inden for forskellige områder og også indenfor områder, som var nært beslægtede. Lægerne fremstod derfor som en gruppe med stor variation af færdigheder. Artikel 3 beskriver udviklingen af en intervention, som bestod af et videreuddannelsesmøde og et elektronisk beslutningsstøtteværktøj. Begge dele blev udviklet på baggrund af foreliggende evidens fra arbejdsgrupper, som bestod af forskellige fagfolk. I pilot-testningen af interventionen var deltagelsesprocenten til videreuddannelsesmødet på 14 %, og 5 % tilmeldte sig det elektroniske beslutningsstøtteværktøj, som blev lukket ned før planlagt på grund af ydre faktorer uden relation til studiet.

### **Konklusion**

Denne afhandling konkluderer, at praktiserende læger er vigtige i den palliative behandling. Praktiserende læger føler sig generelt fortrolige med den palliative behandling, selvom der er variation i deres evner og behandling. Der er derfor nødvendigt at styrke og øge den palliative behandling i almen praksis for at sikre, at patienterne i højere grad får opfyldt deres ønske om at være hjemme i den sidste del af livet og at dø i eget hjem

