Provision of end-of-life care in general practice

PhD dissertation

Anna Kirstine Winthereik

Health
Aarhus University
2016
PROVISION OF END-OF-LIFE-CARE IN GENERAL PRACTICE

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Provision of end-of-life care in general practice

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Financial support:
This project was funded by the Danish Cancer Society and the Danish foundation TrygFonden through the joint grant ‘Safety in Palliative Care’ (Tryghed i palliative forløb)
ACKNOWLEDGEMENT

This PhD study was conducted during my employment at the Oncology Department, Aarhus University Hospital, Aarhus, Denmark, from December 2012 until September 2016.

I am so grateful for having been granted this opportunity to conduct research about the importance of general practitioners’ role in end-of-life care. This study has involved many people, whom I would like to thank, as I would never have accomplished it on my own.

I wish to thank my three supervisors for trusting in me to take on this study. I am thankful for your introduction to the scientific world of palliative care and general practice. I admire you all for your persistent dedication to perform sound research. Thank you for your patience and for staying with me when there was a heavy sea running and the project almost capsized. Because of your support and ideas, we got the project back on an even keel and were able to carry on. Finally, I wish to thank the three of you for your understanding of my need to go on a voyage in the middle of the programme and helping to make my dream come true. I am confident that the peacefulness from the Pacific Ocean helped me through a lot of the challenges I faced during my PhD study.

I wish to thank all people at ‘EKO’ and the Research Unit for General Practice for helping me and making everyday cheerful. A special thanks to Christina, Louise, Kia, Marianne, Mette, Esben, Jakob, and the ladies from ‘Riddersalen’, with whom I was fortunate enough to share an office and life’s ups and downs with during the past years. Also a special thanks to ‘PIP’ for sharing a common interest in palliative care research and life as a PhD student in general. I will miss you all.

I would also like to express my gratitude to the inspiring Professor Miriam Johnson, University of Hull, UK, who invited me to come to Hull and work on my project.

I wish to thank Lone Niedziella, Andreas Boelsmand, and Edwin Spencer for excellent linguistic support and improving my English, and Emil Christian Gram for excellent and patient help improving my graphics.

A thank you to all the GPs who took a part in my work by pilot-testing the questionnaire, answering the questionnaire, attending one of the continuing medical education sessions, or signing up for the electronic decision support.

A special thanks to my dear family and all my friends for all your love, support, and patience. Thank you for being there and showing me that before palliative care there is a lot of life to live and love to give. I am so very grateful to have you all – and I look forward to finally being able to spend time with you all again.

Last but not least, thank you Bo – you make me smile every single day.

Finally, I am so glad that my dissertation overall confirms “GPs are the diamonds” and I look forward to becoming one myself.

[Signature]
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PREFACE
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.
OUTLINE OF THE DISSERATION

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

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.
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).
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.
An international comparative study found that the availability of GPs, among other 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.

### 1.2 GPS AND END-OF-LIFE CARE

#### 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.

### 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.

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

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.
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)
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.
1.3 SUPPORT TO GPS IN THE PROVISION OF END-OF-LIFE CARE

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 been 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.

1.4 BACKGROUND AT A GLANCE

- 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.

### 1.5 AIMS OF THE DISSERTATION

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.

### 2.1 SETTING

#### 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].

### 2.2 OVERVIEW OF THE PAPERS

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**

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

*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 (1st quartile) and 20 bed-days or more (3rd 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 ≥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.

2.4 PAPER II

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 approach 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.

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

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
Methods and materials

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.

2.5 PAPER III

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 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 itself 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.
2.6 THE REGISTERS AND DATA BASES

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.

2.7 DATA ENTRY AND STORAGE

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.
2.8 SIGNIFICANCE LEVEL AND STATISTICAL SOFTWARE

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].

2.9 RESEARCH APPROVALS

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

95%CI: 95% confidence interval, \(^1\)adjusted for calendar year, patient age, civil status, and degree of urbanisation.
Results

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>
<thead>
<tr>
<th>Table 3.2. Place of death for all included deceased cancer patients in per cent (n=116,677)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital/hospice</td>
</tr>
<tr>
<td>Residence(^1)</td>
</tr>
<tr>
<td>Known address(^2)</td>
</tr>
<tr>
<td>Unknown address</td>
</tr>
<tr>
<td>Missing</td>
</tr>
</tbody>
</table>

\(^1\) residence includes home and nursery home

\(^2\) address of death was known e.g. home of a relative

<table>
<thead>
<tr>
<th>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)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Group 1 (lowest)</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Dying at home</td>
</tr>
<tr>
<td>OR, unadjusted (95%CI)</td>
</tr>
<tr>
<td>OR, adjusted(^1) (95%CI)</td>
</tr>
<tr>
<td>Dying at home (incl. missing values)</td>
</tr>
<tr>
<td>OR, unadjusted (95%CI)</td>
</tr>
<tr>
<td>OR, adjusted(^1) (95%CI)</td>
</tr>
</tbody>
</table>

\(^1\) 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)

<table>
<thead>
<tr>
<th>Group</th>
<th>Capital region (n= 22,087 deceased cancer patients)</th>
<th>OR, unadjusted (95%CI)</th>
<th>OR, adjusted1 (95%CI)</th>
<th>&gt;50,000 (n=15,176 deceased cancer patients)</th>
<th>OR, unadjusted (95%CI)</th>
<th>OR, adjusted1 (95%CI)</th>
<th>10,000-49,999 (n=27,370 deceased cancer patients)</th>
<th>OR, unadjusted (95%CI)</th>
<th>OR, adjusted1 (95%CI)</th>
<th>1,000-9,999 (n=29,924 deceased cancer patients)</th>
<th>OR, unadjusted (95%CI)</th>
<th>OR, adjusted1 (95%CI)</th>
<th>&lt;999 (n=21,849 deceased cancer patients)</th>
<th>OR, unadjusted (95%CI)</th>
<th>OR, adjusted1 (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1 (lowest)</td>
<td></td>
<td></td>
<td></td>
<td>Group 2</td>
<td></td>
<td></td>
<td>Group 3</td>
<td></td>
<td></td>
<td>Group 4 (highest)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OR, unadjusted (95%CI)</td>
<td>1 (reference)</td>
<td>1.09 (1.01; 1.17)</td>
<td>1.16 (1.08; 1.26)</td>
<td>1.23 (1.14; 1.33)</td>
<td></td>
<td></td>
<td>1.08 (1.00; 1.17)</td>
<td>1.16 (1.07; 1.25)</td>
<td>1.22 (1.13; 1.31)</td>
<td></td>
<td>1.09 (0.91; 1.07)</td>
<td>1.11 (1.01; 1.21)</td>
<td>1.18 (1.07; 1.29)</td>
<td>1.12 (1.04; 1.20)</td>
<td>1.19 (1.13; 1.28)</td>
</tr>
</tbody>
</table>

*based on locality defined as a distinct population cluster, 95%CI: 95% confidence intervals
1adjusted 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).

<table>
<thead>
<tr>
<th>I feel confident about being a key worker in palliative trajectories</th>
<th>I am proactive in identifying patients with palliative needs</th>
<th>I take the initiative to talk to my patients about dying</th>
<th>I know where my patients suffering from severe disease want to die</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (95% CI)</td>
<td>n (95% CI)</td>
<td>n (95% CI)</td>
<td>n (95% CI)</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>141 (25.3 (21.7; 28.9)</td>
<td>82 (14.7 (11.7; 17.6)</td>
<td>69 (12.3 (9.6; 15.1)</td>
</tr>
<tr>
<td>Agree</td>
<td>284 (51.0 (46.8; 55.2)</td>
<td>252 (45.1 (40.9; 49.2)</td>
<td>256 (45.8 (41.7; 50.0)</td>
</tr>
<tr>
<td>Neither nor disagree</td>
<td>114 (20.6 (17.1; 23.8)</td>
<td>170 (30.4 (26.6; 34.2)</td>
<td>187 (33.5 (29.5; 37.4)</td>
</tr>
<tr>
<td>Strongly disagree</td>
<td>18 (3.2 (1.8; 4.7)</td>
<td>55 (9.8 (6.3; 10.9)</td>
<td>47 (8.4 (6.1; 10.7)</td>
</tr>
<tr>
<td>Total</td>
<td>557 (100)</td>
<td>559 (100)</td>
<td>559 (100)</td>
</tr>
</tbody>
</table>

1Missings 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%).
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
c 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.

3.3. PAPER III

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, 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

<table>
<thead>
<tr>
<th>Time</th>
<th>Curriculum covered in each session</th>
</tr>
</thead>
</table>
| 4.30–5.10 pm | **What is palliative care?**  
- Definition and changes in the understanding of palliative care. Focus on end-of-life care  
- Disease trajectories and the challenges in identifying when end-of-life care is needed  
- Discussion of patient case: (short film) |
| 5.25–6.00 pm | **What are the patients’ palliative needs?**  
- Results from a Danish survey among palliative patients  
- Discussion of two patient cases (short films) |
| 6.30–6.45 pm | **Presentation of the local palliative team by the palliative physician** |
| 6.45–7.35 pm | **Medical skills and practicalities**  
- Prescription of just-in-case\(^1\) box, terminal declaration\(^2\), use of EDS, etc. |
| 7.45–8.00 pm | **Local support to patients and relatives**  
- Which alternatives does the GP have? Who else can help and support? |
Figure 3.2. The EDS pop-up window generated in the medical records to be filled in by GP.

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.

<table>
<thead>
<tr>
<th>Cancer patients</th>
<th>Patients with COPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>CPR-Number</td>
</tr>
<tr>
<td>Sheet Lautrup</td>
<td>900033-xxx</td>
</tr>
<tr>
<td>Frank Teiggen</td>
<td>030538-xxx</td>
</tr>
<tr>
<td>Marianne Jakobs</td>
<td>040933-xxx</td>
</tr>
<tr>
<td>Hanne Pedersen</td>
<td>300244-xxx</td>
</tr>
<tr>
<td>Ole Nielsen</td>
<td>130655-xxx</td>
</tr>
<tr>
<td>Preben Hansen</td>
<td>180538-xxx</td>
</tr>
<tr>
<td>Lone Pedersen</td>
<td>190711-xxx</td>
</tr>
<tr>
<td>Jemmi Nielsen</td>
<td>220037-xxx</td>
</tr>
</tbody>
</table>

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.

4.1 PAPERS I AND II

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 in 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.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital/hospice</td>
<td>47.7</td>
<td>47.9</td>
<td>47.9</td>
<td>46.5</td>
<td>46.6</td>
<td>48.7</td>
<td>45.7</td>
<td>45.4</td>
<td>45.5</td>
</tr>
<tr>
<td>Residence*</td>
<td>42.8</td>
<td>42.8</td>
<td>42.8</td>
<td>30.3</td>
<td>28.8</td>
<td>37.2</td>
<td>26.0</td>
<td>26.5</td>
<td>26.8</td>
</tr>
<tr>
<td>Known address</td>
<td>1.1</td>
<td>1.1</td>
<td>1.2</td>
<td>4.1</td>
<td>4.6</td>
<td>5.3</td>
<td>4.6</td>
<td>4.7</td>
<td></td>
</tr>
<tr>
<td>Unknown address</td>
<td>1.0</td>
<td>1.1</td>
<td>0.7</td>
<td>0.6</td>
<td>0.7</td>
<td>0.6</td>
<td>0.6</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>7.3</td>
<td>7.1</td>
<td>7.3</td>
<td>18.5</td>
<td>19.4</td>
<td>8.6</td>
<td>23.1</td>
<td>23.0</td>
<td>22.4</td>
</tr>
<tr>
<td>Deceased persons</td>
<td>54,076</td>
<td>53,293</td>
<td>53,842</td>
<td>54,369</td>
<td>53,410</td>
<td>53,723</td>
<td>53,526</td>
<td>51,597</td>
<td>51,188</td>
</tr>
</tbody>
</table>

*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 deceases 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 is 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.
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]. 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].

4.2 PAPER III

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
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 exiting 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.
4.3 GENERALISABILITY

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.
5.1 PAPER I

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].

5.2 PAPER II

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.

5.3 PAPER III

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 issue 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 spent 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 combing 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
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.
DANSK RESUME

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

Praktiserende læger og palliation i den sidste del af livet

Baggrund


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 kræftpatients 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 lærer i Region Midtjylland om deres fortrolighed med palliativ behandling. Artikel 3 omhandlede udviklingen af en kompleks intervention, som havde til formål at støtte praktiserende lærer i palliativ behandling. Interventionen blev udviklet ud fra den guideline, som det britiske forskningsråd (MRC) har udarbejdet for komplekse interventioner.

**Resultater**


**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.
PAPER I

HOME VISITING PROPENSITY AMONG GENERAL PRACTITIONERS AND ASSOCIATIONS WITH CANCER PATIENTS’ PLACE OF CARE AND DEATH

Submitted to ‘British Journal of Cancer’
Home visiting propensity among general practitioners and associations with cancer patients’ place of care and death

Running title: GP home visiting and end-of-life cancer care

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Number of words: 3495

Number of tables/figures: 3

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Abstract (structured 200 words)

Background

Previous studies of associations between home visits by general practitioners (GPs) and end-of-life care for cancer patients have been subject to confounding. We analysed associations between GPs’ propensity to pay home visits and the likelihood of hospitalisation and dying outside hospital among their cancer patients.

Methods

We performed a Danish national register-based cohort study based on data collected in 2003-2012. Standardised incidence rates of GP home visits were calculated as a measure for propensity. Practices were grouped into propensity quartiles. Associations between groups and end-of-life outcomes for cancer patients were calculated.

Results

We included 2,670 practices with 2,518,091 listed patients (18,364,679 person years); 116,677 died from cancer. The GPs’ propensity to pay home visit varied 6.6-fold between groups. Cancer patients in Group 4 (highest propensity) were less hospitalized than patients in Group 1 (lowest propensity): OR: 1.13 (95% CI: 1.08; 1.17) for ≤3 bed-days and OR: 0.95 (95% CI: 0.91-0.99) for ≥20 bed-days. Group 4 patients were more likely to die out of hospital (OR: 1.20 (95% CI: 1.16; 1.24)) than Group 1.

Conclusion

We found a dose-response-like association between GPs’ propensity to pay home visit and their patients’ likelihood of less end-of-life hospitalisation and dying out of hospital.

Keywords: Denmark, general practice, home visits, palliative care, end-of-life care, cancer, place of death, place of care
Introduction


Danish general practitioners (GPs) are responsible for primary care, including end-of-life medical care at home. Therefore, the role of the GP is crucial when aiming at fulfilling the patient’s preferences. More than 98% of Danes are listed with a specific general practice, which should be consulted for medical advice (unless in emergencies). The GPs serve as gatekeepers to the rest of the health care system [Pedersen et al, 2012], and they hold a pivotal position as they manage the basic end-of-life care, often in collaboration with other health care professionals.

GP involvement in end-of-life care has been found to be positively associated with the patient’s likelihood of dying at home [Brazil et al, 2002, Burge et al, 2003, Neergaard et al, 2009]. Particularly home visits by the GP seem to be strongly associated with the likelihood of dying at home among cancer patients [Brazil et al, 2002, Neergaard et al, 2009, Aabom et al, 2005]. However, these previous studies are likely to have been affected by confounding by indication; home visits may have been paid because the GP knew that the patient had a strong preference for dying at home and thus a fair possibility of dying at home. Such bias could be minimised by using the GPs’ propensity for doing home visits in general.

We aimed at assessing the association between GPs’ propensities to pay home visits in general and their listed cancer patients’ likelihood of hospitalisation during the last three months of life and their likelihood of dying out of hospital.
Methods

Design

We performed a national register-based cohort study based on data collected in 2003-2012. The estimated general propensity of the included GPs to perform home visits during one year was used as an ecological exposure of end-of-life outcomes in those of their cancer patients who died in the subsequent year. The analyses consisted of two steps. First, we ranked general practices into four groups; these were divided by quartiles based on the yearly standardised rate of home visits during daytime. Second, associations were estimated between these four groups and the likelihood of hospitalisation and dying out of hospital among their cancer patients. We hypothesised that a higher propensity of home visits would lead to less hospitalisation and more deaths outside hospital.

Setting

The study was carried out in Denmark, where access to health care services is free and tax-financed. The Danish GPs are self-employed and remunerated by the national health insurance system through a mix of capitation and fee-for-service using a unique provider number. GPs may work in partnership practices or single-handed practices [Pedersen et al, 2012].

Study population

Cohort 1: In the first step, Danish citizens living in Denmark in 2003 and listed with a general practice were included, and these data were used to calculate the total number of person-years for every practice. The persons were eligible at the beginning of the study if they were 40 years or above or from when they turned 40 years in the study period (2003-2011), whichever came last. The study was restricted to this age group as persons dying of cancer in Denmark before the age of 40 in 2013 constituted only 1% of all cancer deaths [Nordcan]. Included persons contributed with person-years to the practice at which they were listed.
at any given time from the time of inclusion in the study until emigration, leaving the list system, termination of study, or death, whichever came first.

Cohort 2: In the second step, the study population consisted of persons included in Cohort 1 who had died of cancer from 2004 to 2012 and been listed with the same general practice for at least six months prior to death. The last criteria were chosen to ensure that the persons included in the cohort had the possibility of receiving home visits and getting acquainted with their GP prior to death. Death of cancer was defined as any cancer stated as one of the causes of deaths on the death certificate: codes C00-97, D32-33, D42-43 according to the International Classification of Diseases of 2010 (ICD-10) by the World Health Organization (WHO) [WHO’s International Classification of Diseases (ICD))] (excluding accidents, homicides, and suicides).

Data

Data were retrieved from national registers and linked using the unique personal registration number allocated to every Danish citizen at birth or immigration [Pedersen, 2011]. Practice affiliation for each patient was available from the Patient List Register, which contains information about which practice the patient is listed with for which time period. This allowed us to calculate the exact contribution of person-years and identify patient characteristics for every practice while taking into account change of practice. Information on home visits paid by GPs to their patients aged 40 or above (Cohort 1) in the period was retrieved from the Danish National Health Service Register based on the codes used for remuneration of home visits [Andersen et al, 2011]. Data on patient characteristics were retrieved for each year and included patient age (on 1 January every year), sex, educational level, income, and degree of urbanisation in the area of living. Civil status was retrieved from Statistics Denmark [Statistics Denmark, b]. Data on diagnoses to calculate Charlson’s comorbidity index (CCI) and days of hospitalisation were retrieved from the Danish National Patient Register [Lynge et al, 2011]. Data on place and cause of death were collected from the Danish Register of Causes of Death, which holds information on all death certificates [Helweg-Larsen, 2011]. An electronic death certificate was introduced in Denmark in 2007.
**Analyses**

The analyses were done in two steps. The first step was to calculate the general propensity of the individual practice to pay home visits as the exposure. This was calculated as a standardised incidence rate (SIR) defined as: observed home visits in a specific year divided by the expected number of home visits in relation to observation time in the practice population each year. This was done yearly from 2003 to 2011. The expected number of home visits was calculated using a Poisson regression on the basis of data from all practices adjusted for the composition of the patient populations with regard to: patient age, educational level (<10 years, 10–15 years, >15 years), income (disposable income categorised in quartiles [Statistics Denmark, a]), degree of urbanisation in area of living (based on clusters of population density: capital city, >50,000, 10,00-49,999, 1,000-9,999, < 999), and comorbidity (CCI: 0, 1-2, or ≥3). CCI [Charlson et al, 1987] was calculated for every person based on the medical history ten years prior to each of the years from 2003 to 2011 (see eTable 2).

Information concerning educational level was missing in 5% of the cases, primarily among the oldest persons. The majority of the oldest persons did not have an education longer than 10 years, and missing values were hence recoded to the lowest educational level. We identified approximately 0.5% missing values for the remaining variables, and this low figure made imputation irrelevant.

Practices were ranked by their SIR and categorised into four groups divided by quartiles for each year. These four groups were compared using descriptive statistics.

In the second step, the associations between the propensity to pay home visits in the preceding year and place of care and death for deceased cancer patients in 2004-2012 were estimated using logistic regression models. Group 1 (lowest propensity) was used as reference group for groups 2, 3, and 4 (highest propensity). The palliative outcomes were days spent in hospital during the last three months of life and
dying out of hospital. Two dichotomised variables for days spent in hospital in the last three months of life were created based on the lower and the upper quartile: having spent 3 days or less (yes/no) and 20 days or more (yes/no). The associations between propensity and bed-days were adjusted for age of the patient, degree of urbanisation, calendar year, and comorbidity (cancer diagnoses were removed from the CCI for this analysis). We also calculated the average number of hospital admissions during the last three months of life for each of the four groups.

Place of death was registered as death on hospital, residence, known address, unknown address or missing value. We dichotomised the variable as death out of hospital or not. The association between propensity to pay home visits and death out of hospital was adjusted for age of the patient, degree of urbanisation, calendar year, comorbidity (cancer diagnoses were removed from the CCI for this analysis), and civil status.

In subsequent analyses we assessed the possible consequences of missing values in place of death by changing the dichotomisation in outcome (death at home or not, and death at home including missing or not) and by testing the associations in three time periods (2004-2006 before the electronic death certificate, 2009 when data was manually registered and more complete, and 2007-2008 and 2010-12 after the introduction of the electronic death certificate). Finally, we repeated the analysis for every degree of urbanisation to investigate potential interaction.

Results

Home visits

We included 2,670 general practices with a total of 2,518,091 patients during the study period (cohort 1). The average observation time was 8.73 years per person (total observation time: 18,364,679 person-years). The included patients received 727,457 home visits in total, and the propensity to pay home visits varied 6.6-fold between Group 1 (SIR: 0.50) and Group 4 (SIR: 3.28) (Table 1). The patient populations were comparable between the practice groups with regard to age, gender, comorbidity, income, and educational
level (Table 1). However, for degree of urbanisation, we observed a tendency in Group 1 towards having more patients living in urban areas than the other three groups (Table 1).

End-of-life hospitalisation and place of death

A total of 116,677 persons died of cancer in the years from 2004 to 2012. The characteristics of the deceased patients were comparable between the four practice groups, except for degree of urbanisation (Table 2). We found a dose-response-like association between the GP’s propensity to pay home visits and both length of hospitalization in the last three months and likelihood of dying out of hospital among their listed patients (Table 3). Patients in Group 1 spent on average 13.8 days in hospital, and this was significantly lower for patients in Group 4 with 13.2 days (Table 3). When hospitalised, Group 4 cancer patients had a higher likelihood of being hospitalised for only three days or less (OR: 1.13 (95% CI: 1.08; 1.17)) and a lower likelihood of having 20 or more bed-days (OR: 0.95 (95% CI: 0.91-0.99)). The OR for dying out of hospital was 1.20 (95%CI: 1.16; 1.24) in Group 4 compared to Group 1 (Table 3). Patients in Group 1 had significantly more hospital admissions than patients in Group 4 (mean: 2.58 vs. 2.52).

Using the dichotomisation “death at home or not” instead of “death outside hospital or not” gave the same dose-response associations and very similar estimates (data not shown). We found no differences between the three time periods (data not shown).

For each of the five degrees of urbanisation, the analysis showed the same overall trend; the GP’s propensity to pay home visits was associated to the patients’ duration of hospitalisation during the last three months of life and their place of death, although not all performed analyses reached statistical significance (data not shown).

Discussion

The propensity to pay home visits varied more than 6-fold between the general practices. A higher propensity was significantly associated with a higher likelihood among the cancer patients of having shorter
stay at the hospital and dying out of hospital. Few hospitalisations and not dying in hospital are in general considered optimal in the light of most patients’ preferences at the end of life. In the GP group providing most home visits, five percentage points more cancer patients died out of hospital compared to the patient group for which GPs made less home visits. To our knowledge, this is the first study to show this association while taking into account the risk of confounding by indication.

Strengths and limitations
The strengths of the study were the national population-based design and the complete inclusion of all Danish citizens through the Danish civil registration number, as this approach ensured that there was no selection bias. The civil registration number allowed exact linkage between reliable national registers with few missing values, apart from education. Information about home visits paid by GPs was based on remuneration, which increases the completeness and the validity of the data.

Another important strength was the ecological design with estimation of the propensity to pay home visits calculated independently of the deceased patients. Opposite a cohort study counting home visits for the individual patients who died of cancer, this design prevented confounding by indication. Furthermore, we used the propensity from the preceding year to examine the association of deceased persons in the subsequent year, which added further strength to the design. The design allowed us to create a natural experiment by exploiting the natural variation among GPs in terms of their individual propensity to pay home visits. The underlying assumption was that the patient’s choice of GP was independent of the GP’s propensity to pay home visits as no public information is available about number or rates of home visits paid by GPs. Another assumption was that the GPs had the same options for providing home visits and most likely also similar demands among their patients.

We found that more practices in the Capital Region of Denmark were paying less home visits than practices in rural areas. However, our stratified analyses showed that the same association was found between
propensity of home visits and end-of-life outcomes, irrespective of the number of inhabitants in this particular geographic area.

A limitation was the quality of the data for “place of death” as we found an increasing proportion of missing values for this category after the introduction of the electronic death certificate. With regard to the missing values, the proportion of persons dying in hospital was almost constant throughout the period. Additionally, the more structured procedure of registering deaths in hospitals made us assume that these registrations were more reliable. To account for potential differential misclassification with regard to missing values on place of death, we adjusted for calendar year and used “death out of hospital” as an outcome. The different analyses of place of death did not indicate any changes in the association when focusing on home death or the three different time periods. Our results are, therefore, consistent.

From 2007 and onwards hospice death was registered as death on hospital. However, only few died on hospice. The first Danish hospice was funded in 1995 and there were a total of 158 beds on hospices nationally in 2009 [Timm et al, 2012]. The analyses performed for different time made no differences to the estimates or the conclusion. Hence the misclassification did not have an impact on the association. We chose to combine all other places of death than hospital/hospice into one outcome under the assumption that a GP was responsible for medical treatment in these settings.

Another limitation was that data were linked at practice level and not to an individual GP. For practices with more than one GP, the propensity was an average; this could lead to an underestimation of the associations. Some of the practices might have changed ownership during a calendar year, which we were unable to account for. As GPs own their own practice in Denmark, the turnover was limited and hence the impact of this bias is considered to be very small. We further reduced this potential bias by using propensity on a yearly basis.
The populations in the four groups of practices were very similar, apart from degree of urbanisation as more patients in urban areas were listed with practices with low propensity to pay home visits. GPs in rural areas have previously been shown to have a higher rate of home visits than GPs in urban areas [Boerma and Groenewegen, 2001, Neergaard M. et al, 2015]. Hence, some residual confounding might have been present. To investigate this further, we repeated the analysis for every degree of urbanisation and found the same positive dose-response pattern within all strata. Hence, there was no indication of interaction of degree of urbanisation.

Comparisons with other studies

A European comparative study proposed that GP availability was partly related to the cancer patient’s place of death [Cohen et al, 2015]. We found a 6-fold variation in the propensity to pay home visits between the practice groups. To our knowledge, the research on variation in home visits at practice level is very limited. The variation was found to be 8-fold in an English study based on 60 practices [Aylin et al, 1996], which is comparable to our findings.

Previous studies found that the number of home visits paid by GPs in the palliative trajectory was associated with place of death for their cancer patients [Kronman et al, 2008, Neergaard et al, 2009, Aabom et al, 2005]. However, these studies were register-based cohort studies, and GP home visit rates were based on visits to the deceased cancer patients. These designs induce confounding by indication as GPs may provide more visits to the patients who can and who wish to die at home. Neergaard et al found a prevalence ratio (PR) of 4.5 (95% CI: 1.3; 15.6) for dying at home when comparing whether or not the patient received any home visits by the GP [Neergaard et al, 2009]. The PR for dying at home increased with number of home visits. Aabom et al. found a similar inverse association between GP home visits and the patient dying in hospital (OR: 0.08 (95% CI: 0.06; 0.12)) by comparing patients who received home visits and patients who did not [Aabom et al, 2005]. This strong association can indeed indicate a selection of patients in that study (confounding by indication). Our results correspond to these findings. Yet, as our
results are not subject to confounding by indication, the association found in our study between home
visits and end-of-life care becomes more reliable. Further, the dose-response relationship that we
identified reflects differences in the propensity among GPs and not differences in numbers of home visits
paid to patients. Hence, our finding reflects a basic GP characteristic rather than a coincidental use of home
visits.

We found that the GPs’ propensity to pay home visits was associated with hospitalisation at the end of life
for cancer patients. Kronman et al. showed a similar association between a higher number of home visits
and fewer hospital days at the end of life; they even found that home visits let to lower costs and fewer
preventable hospitalisations for patients suffering from non-malignancies [Kronman et al, 2008]. These
findings are important for at least two reasons; many patients prefer to be at home at the end of life, and
the palliative pathways may be more efficient. Our findings draw attention to the potential importance of
GPs’ home visits in preventing hospitalisation. As a rough estimate on possible preventable hospitalisations,
the calculated difference (a mean of 0.6 bed-days per deceased cancer patient) between Group 1 and 4
corresponds to a total reduction of 4.3% bed-days for patients in Group 1. This is a considerable number
when taking the total number of 1,571,995 bed-days into account. In continuation of this, the findings may
suggest that the GPs’ propensity to pay home visits could be associated with number of hospital
admissions, which is important for a successful end-of-life trajectory. However, our data did not allow us to
analyse the reasons for admission as this would have required an indication of preventable admission.
Further investigations focusing on this issue are very relevant.

Implications

The results of this study support that GPs doing more home visits may ensure that more cancer patients
have their wishes for end-of-life care fulfilled. This emphasises the need to consider how to support GPs in
providing home visits and palliative care to cancer patients. Further research is needed to investigate the
mechanisms behind our findings to identify whether it is caused by home visits per se, certain GPs characteristics, or different way of organising the clinical work.

Conclusion

The GPs’ propensity to pay home visits was positively associated with their patients’ likelihood of having few bed-days at hospital during the last three months of their life and dying out of hospital.

Acknowledgements

We would like to thank the Danish Cancer Society and the Danish foundation TrygFonden for financial support. We thank data manager Kaare Rud Flarup, Research Centre for Cancer Diagnosis in Primary Care, Research Unit for General Practice, Aarhus University, Denmark for helping with the data, and Lone Niedziella for linguistic revision.

Approvals

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)

Availability of data and materials

The datasets generated and analysed during the current study are not publicly available due restriction from the Danish Data Protection Agency.

Funding

The Danish Cancer Society and the Danish foundation TrygFonden supported the study through the joint grant ‘Safety in Palliative Care’ [Tryghed i palliative forløb]. The funding body did not have a role in either
the design of the study, the data collection, analyses and interpretation of data nor in the writing of the manuscript.

**Competing interest**

The authors declare that they have no competing interests
References


(Accessed at 14 December 2015)

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Table 1. Practices (n=2,670) divided into four groups based on GP propensity to pay home visits and the characteristics of their patients (n=2,518,091). The observation time was from 2003-2011.

<table>
<thead>
<tr>
<th>Characteristics of patient composition</th>
<th>Total</th>
<th>Group 1 (Lowest propensity)</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4 (Highest propensity)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation time on practice level, (years)</td>
<td>18,364,679</td>
<td>4,308,543</td>
<td>5,722,968</td>
<td>5,036,178</td>
<td>3,746,990</td>
</tr>
<tr>
<td>Home visits, (n)</td>
<td>727,457</td>
<td>97,031</td>
<td>181,511</td>
<td>219,639</td>
<td>229,294</td>
</tr>
<tr>
<td>Standardised incidence rate for home visits (SIR), (mean)</td>
<td>1.44</td>
<td>0.50</td>
<td>0.85</td>
<td>1.14</td>
<td>3.28</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age, year (median (iqr^1))</th>
<th>59.5 (17.2)</th>
<th>59.5 (17.1)</th>
<th>59.6 (17.1)</th>
<th>59.5 (17.1)</th>
<th>59.4 (17.2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (%)^2</td>
<td>48.6</td>
<td>48.4</td>
<td>47.6</td>
<td>48.2</td>
<td>48.5</td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Educational level, (%)^3</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>&lt; 10 years</td>
<td>38.6</td>
<td>38.7</td>
<td>38.8</td>
<td>38.0</td>
<td>38.8</td>
</tr>
<tr>
<td>10-15 years</td>
<td>43.5</td>
<td>43.5</td>
<td>43.6</td>
<td>43.5</td>
<td>43.2</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>18.0</td>
<td>17.8</td>
<td>17.6</td>
<td>18.5</td>
<td>18.0</td>
</tr>
<tr>
<td>Income level, (%)^2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Quartile (lowest income)</td>
<td>24.1</td>
<td>24.2</td>
<td>24.0</td>
<td>23.7</td>
<td>24.4</td>
</tr>
<tr>
<td>2. Quartile</td>
<td>24.9</td>
<td>25.1</td>
<td>25.0</td>
<td>24.6</td>
<td>24.9</td>
</tr>
<tr>
<td>3. Quartile</td>
<td>25.4</td>
<td>25.3</td>
<td>25.5</td>
<td>25.5</td>
<td>25.3</td>
</tr>
<tr>
<td>4. Quartile (highest income)</td>
<td>25.6</td>
<td>25.3</td>
<td>25.5</td>
<td>26.3</td>
<td>25.3</td>
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<tr>
<td>Degree of urbanisation^4, (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Capital city</td>
<td>17.6</td>
<td>21.7</td>
<td>15.2</td>
<td>15.7</td>
<td>18.4</td>
</tr>
<tr>
<td>&gt;50,000</td>
<td>12.2</td>
<td>14.3</td>
<td>11.9</td>
<td>10.9</td>
<td>12.2</td>
</tr>
<tr>
<td>10,000-49,999</td>
<td>22.3</td>
<td>22.2</td>
<td>22.9</td>
<td>24.2</td>
<td>18.7</td>
</tr>
<tr>
<td>1,000-9,999</td>
<td>24.5</td>
<td>21.4</td>
<td>25.9</td>
<td>25.9</td>
<td>24.5</td>
</tr>
<tr>
<td>&lt;999</td>
<td>22.9</td>
<td>20.4</td>
<td>23.9</td>
<td>23.0</td>
<td>25.4</td>
</tr>
<tr>
<td>Comorbidity, (%)^4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>79.1</td>
<td>78.2</td>
<td>78.9</td>
<td>79.6</td>
<td>79.9</td>
</tr>
<tr>
<td>1-2</td>
<td>17.0</td>
<td>17.6</td>
<td>17.1</td>
<td>16.7</td>
<td>16.6</td>
</tr>
<tr>
<td>&gt;=3</td>
<td>3.8</td>
<td>4.2</td>
<td>3.9</td>
<td>3.7</td>
<td>3.6</td>
</tr>
</tbody>
</table>

^1iqr: Interquartile range  
^2Missing values were included in the total, but not in the four individual groups  
^3Degree of urbanisation is based on clusters of population in line with United Nation’s definition of population density and urbanisation  
^4Comorbidity is based on Charlson’s comorbidity index
Table 2. Characteristics of deceased cancer patients in 2004-2012 in the four practice groups based on variations in the GP propensity (SIR)\(^1\) to pay home visits.

<table>
<thead>
<tr>
<th>Characteristics of patients</th>
<th>Total</th>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased patients, (n)</td>
<td>116,677 (100)</td>
<td>25,608 (21.9)</td>
<td>32,809 (28.1)</td>
<td>32,138 (27.5)</td>
<td>26,122 (22.4)</td>
</tr>
<tr>
<td><strong>Characteristics of patients</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, year, (median (iqr(^2)))</td>
<td>73.4 (16.5)</td>
<td>73.2 (16.5)</td>
<td>73.4 (16.4)</td>
<td>73.5 (16.5)</td>
<td>73.7 (16.8)</td>
</tr>
<tr>
<td>Sex, (n (%))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>59,882 (51.3)</td>
<td>13,021 (50.9)</td>
<td>16,829 (51.3)</td>
<td>16,581 (51.6)</td>
<td>13,451 (51.5)</td>
</tr>
<tr>
<td>Civil status, (n (%))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohabiting</td>
<td>60,552 (51.9)</td>
<td>13,284 (51.9)</td>
<td>17,316 (52.8)</td>
<td>16,741 (52.1)</td>
<td>13,211 (50.6)</td>
</tr>
<tr>
<td>Living alone</td>
<td>56,094 (48.1)</td>
<td>12,315 (48.1)</td>
<td>15,486 (47.1)</td>
<td>15,387 (47.9)</td>
<td>12,906 (49.4)</td>
</tr>
<tr>
<td>Educational level, (n (%))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 10 years</td>
<td>65,541 (56.2)</td>
<td>14,231 (55.6)</td>
<td>18,496 (56.2)</td>
<td>18,065 (56.1)</td>
<td>14,776 (56.6)</td>
</tr>
<tr>
<td>10-15 years</td>
<td>40,063 (34.3)</td>
<td>9,007 (35.2)</td>
<td>11,277 (34.4)</td>
<td>10,925 (34.0)</td>
<td>8,854 (33.9)</td>
</tr>
<tr>
<td>More than 15 years</td>
<td>11,073 (9.5)</td>
<td>2,370 (9.25)</td>
<td>3,063 (9.4)</td>
<td>3,148 (9.8)</td>
<td>2,492 (9.5)</td>
</tr>
<tr>
<td>Degree of urbanisation, (n (%))(^3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Capital city</td>
<td>22,073 (19.0)</td>
<td>5,790 (22.7)</td>
<td>5,316 (16.2)</td>
<td>5,442 (17.0)</td>
<td>5,523 (21.3)</td>
</tr>
<tr>
<td>&gt;50,000</td>
<td>15,169 (13.0)</td>
<td>3,919 (15.3)</td>
<td>4,273 (13.1)</td>
<td>3,681 (11.5)</td>
<td>3,296 (12.7)</td>
</tr>
<tr>
<td>10,000-49,999</td>
<td>27,351 (23.5)</td>
<td>5,939 (23.3)</td>
<td>7,747 (23.7)</td>
<td>8,307 (25.9)</td>
<td>5,358 (20.6)</td>
</tr>
<tr>
<td>1,000-9,999</td>
<td>29,910 (25.7)</td>
<td>5,647 (22.1)</td>
<td>9,126 (27.9)</td>
<td>8,611 (26.9)</td>
<td>6,526 (25.1)</td>
</tr>
<tr>
<td>&lt;999</td>
<td>21,842 (18.8)</td>
<td>4,252 (16.6)</td>
<td>6,271 (19.2)</td>
<td>6,028 (18.8)</td>
<td>5,291 (20.4)</td>
</tr>
<tr>
<td>Comorbidity, (n (%))(^4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>65,496 (56.1)</td>
<td>14,431 (56.4)</td>
<td>18,363 (56.0)</td>
<td>18,062 (56.2)</td>
<td>14,640 (56.0)</td>
</tr>
<tr>
<td>1-2</td>
<td>39,965 (34.3)</td>
<td>8,751 (34.2)</td>
<td>11,293 (34.4)</td>
<td>11,003 (34.2)</td>
<td>8,918 (34.1)</td>
</tr>
<tr>
<td>&gt;3</td>
<td>11,216 (9.6)</td>
<td>2,462 (9.5)</td>
<td>3,153 (9.6)</td>
<td>3,073 (9.6)</td>
<td>2,564 (9.8)</td>
</tr>
</tbody>
</table>

\(^1\)SIR: Standardised incidence rate: (observed home visits/expected home visits)/observation time.
\(^2\)Iqr: Interquartile range
\(^3\)Degree of urbanisation is based on clusters of population in line with UN’s definition of population density and urbanisation
\(^4\)Comorbidity was based on Charlson comorbidity index but without including cancer diagnoses
Table 3. Distribution of palliative outcomes and associations between GP propensity to pay home visits and palliative outcomes in 2004-2012 shown in odds ratios (ORs) with 95% confidence intervals (95% CI).

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Group 1 Lowest</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4 Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased patients</td>
<td>116,677</td>
<td>25,608</td>
<td>32,809</td>
<td>32,138</td>
<td>26,122</td>
</tr>
<tr>
<td>Total bed-days</td>
<td>1,571,995</td>
<td>354,779</td>
<td>439,565</td>
<td>432,668</td>
<td>344,943</td>
</tr>
<tr>
<td><strong>Palliative outcomes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hospitalisation the last 3 months of life</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bed-days, days: Median, (1.; 3. quartiles)</td>
<td>10 (3; 20)</td>
<td>10 (3; 20)</td>
<td>10 (3; 20)</td>
<td>10 (3; 20)</td>
<td>10 (3; 19)</td>
</tr>
<tr>
<td>Bed-days, days: adjusted mean (95%CI)</td>
<td>13.5 (13.4; 13.5)</td>
<td>13.8 (13.6; 14.0)</td>
<td>13.4 (13.3; 13.5)</td>
<td>13.5 (13.3; 13.6)</td>
<td>13.2 (13.1; 13.4)</td>
</tr>
<tr>
<td>Having 3 or less bed-days, (n (%))</td>
<td>32,259 (27.7)</td>
<td>6,748 (26.4)</td>
<td>9,178 (28.0)</td>
<td>8,823 (27.5)</td>
<td>7,510 (28.8)</td>
</tr>
<tr>
<td>Having 20 or more bed-days, (n (%))</td>
<td>27,639 (23.7)</td>
<td>6,272 (24.5)</td>
<td>7,684 (23.4)</td>
<td>7,621 (23.7)</td>
<td>6,062 (23.2)</td>
</tr>
<tr>
<td><strong>Place of death:</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital/hospice**</td>
<td>65,483 (56.1)</td>
<td>15,101 (59.0)</td>
<td>18,489 (56.4)</td>
<td>17,808 (55.4)</td>
<td>14,085 (53.9)</td>
</tr>
<tr>
<td>Other incl. missing</td>
<td>51,194 (43.9)</td>
<td>10,507 (41.0)</td>
<td>14,320 (43.7)</td>
<td>14,330 (44.6)</td>
<td>12,037 (46.1)</td>
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<tr>
<td><strong>Associations</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3 or less bed-days (1\textsuperscript{st} quartile)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OR, unadjusted (95%CI)</td>
<td>1 (reference)</td>
<td>1.08 (1.04; 1.12)</td>
<td>1.06 (1.01; 1.10)</td>
<td>1.13 (1.08; 1.17)</td>
<td></td>
</tr>
<tr>
<td>OR, adjusted\textsuperscript{2} (95%CI)</td>
<td>1 (reference)</td>
<td>1.07 (1.03; 1.11)</td>
<td>1.05 (1.01; 1.09)</td>
<td>1.11 (1.07; 1.16)</td>
<td></td>
</tr>
<tr>
<td><strong>20 or more bed-days (3\textsuperscript{rd} quartile)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OR, unadjusted (95%CI)</td>
<td>1 (reference)</td>
<td>0.94 (0.90; 0.98)</td>
<td>0.96 (0.92; 1.00)</td>
<td>0.93 (0.89; 0.97)</td>
<td></td>
</tr>
<tr>
<td>OR, adjusted\textsuperscript{3} (95%CI)</td>
<td>1 (reference)</td>
<td>0.96 (0.92; 1.00)</td>
<td>0.98 (0.94; 1.01)</td>
<td>0.95 (0.91; 0.99)</td>
<td></td>
</tr>
<tr>
<td><strong>Dying out of hospital/hospice</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OR, unadjusted (95%CI)</td>
<td>1 (reference)</td>
<td>1.11 (1.08; 1.16)</td>
<td>1.16 (1.12; 1.20)</td>
<td>1.23 (1.19; 1.27)</td>
<td></td>
</tr>
<tr>
<td>OR, adjusted\textsuperscript{4} (95%CI)</td>
<td>1 (reference)</td>
<td>1.08 (1.04; 1.11)</td>
<td>1.12 (1.08; 1.16)</td>
<td>1.20 (1.16; 1.24)</td>
<td></td>
</tr>
</tbody>
</table>

\textsuperscript{1}Adjusted for age, sex, and comorbidity

\textsuperscript{2}Hospice was registered as hospital death from 2007 and onwards

\textsuperscript{3}Adjusted for calendar year, age, civil status, and degree of urbanisation
Supplementary material:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital/hospice</td>
<td>47.7</td>
<td>47.9</td>
<td>47.9</td>
<td>46.5</td>
<td>46.6</td>
<td>48.7</td>
<td>45.7</td>
<td>45.4</td>
<td>45.5</td>
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<td>Residence¹</td>
<td>42.8</td>
<td>42.8</td>
<td>42.8</td>
<td>30.3</td>
<td>28.8</td>
<td>37.2</td>
<td>26.0</td>
<td>26.5</td>
<td>26.8</td>
</tr>
<tr>
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<td>1.1</td>
<td>1.2</td>
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<td>4.6</td>
<td>5.3</td>
<td>4.6</td>
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<td>4.7</td>
</tr>
<tr>
<td>Unknown address</td>
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<td>1.1</td>
<td>0.7</td>
<td>0.6</td>
<td>0.7</td>
<td>0.6</td>
<td>0.6</td>
<td>0.6</td>
<td>0.5</td>
</tr>
<tr>
<td>Missing values</td>
<td>7.3</td>
<td>7.1</td>
<td>7.3</td>
<td>18.5</td>
<td>19.4</td>
<td>8.6</td>
<td>23.1</td>
<td>23.0</td>
<td>22.4</td>
</tr>
<tr>
<td>Deceased persons</td>
<td>54,076</td>
<td>53,293</td>
<td>53,842</td>
<td>54,369</td>
<td>53,410</td>
<td>53,723</td>
<td>53,526</td>
<td>51,597</td>
<td>51,188</td>
</tr>
</tbody>
</table>

¹ Residence as place of death includes home and nursing homes.
² Cases in which death occurs on a known address in Denmark which is not the patient's residence or the hospital (e.g. address of a relative or friend). Calculated on the basis of data from the Danish Register of Causes of Death.
<table>
<thead>
<tr>
<th>Condition</th>
<th>ICD-10 codes</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myocardial infarction</td>
<td>I21; I22; I23</td>
<td>1</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>I50; I11.0; I13.0; I13.2</td>
<td></td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>I70; I71; I72; I73; I74; I77</td>
<td></td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>I60-69; G45; G46</td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td>F00-F03; F05.1; G30</td>
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<tr>
<td>Chronic pulmonary disease</td>
<td>J40-J47; J60-J67; J68.4; J70.1; J70.3; J84.1; J92.0; J96.1; J98.2; J98.3</td>
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<tr>
<td>Connective tissue disease</td>
<td>M05; M06; M08; M09; M30; M31; M32; M33; M34; M35; M36; D86</td>
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<tr>
<td>Ulcer disease</td>
<td>K22.1; K25-K28</td>
<td></td>
</tr>
<tr>
<td>Mild liver disease</td>
<td>B18; K70.0-K70.3; K70.9; K71; K73; K74; K76.0</td>
<td></td>
</tr>
<tr>
<td>Diabetes without end-organ damage</td>
<td>E10.0, E10.1; E10.9; E11.0; E11.1; E11.9</td>
<td></td>
</tr>
<tr>
<td>Diabetes with end-organ damage</td>
<td>E10.2-E10.8, E11.2 E11.8</td>
<td>2</td>
</tr>
<tr>
<td>Hemiplegia</td>
<td>G81; G82</td>
<td></td>
</tr>
<tr>
<td>Moderate to severe renal disease</td>
<td>I12; I13; N00-N05; N07; N11; N14; N17-N19; Q61</td>
<td></td>
</tr>
<tr>
<td>Non-metastatic solid tumor¹</td>
<td>C00-C95</td>
<td></td>
</tr>
<tr>
<td>Leukemia¹</td>
<td>C91-C95</td>
<td></td>
</tr>
<tr>
<td>Lymphoma¹</td>
<td>C81-C85; C88; C90; C96</td>
<td></td>
</tr>
<tr>
<td>Moderate to severe liver disease</td>
<td>B15.0; B16.0; B16.2; B19.0; K70.4; K72; K76.6; I85</td>
<td>3</td>
</tr>
<tr>
<td>Metastatic cancer¹</td>
<td>C76-80</td>
<td></td>
</tr>
<tr>
<td>AIDS</td>
<td>B21-24</td>
<td>6</td>
</tr>
</tbody>
</table>

Note: ¹When calculating the CCI for deceased cancer patients, this condition was not included.

Ref. [Charlson et al, 1987]
PAPER II

DANISH GENERAL PRACTITIONERS’ SELF-REPORTED COMPETENCES IN END-OF-LIFE CARE

Accepted for publication in ‘Scandinavian Journal of Primary Health Care’
**Title:** Danish general practitioners’ self-reported competences in end-of-life care

**Authors:** Winthereik, AK¹; Neergaard, MA¹²; Vedsted, P³; Jensen, AB¹

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3. Research Unit for General Practice, Aarhus University, Denmark

**Short running title:** End-of-life care competence in Danish general practice

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Word count: 2999

Tables and figures: 5

References: 30

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Key Points:

GPs are pivotal in end-of-life (EOL) care but their involvement has been questioned. Hence, GPs’ perceived competencies were explored.

- GPs were twice as likely to provide EOL care for patients with cancer than for patients with non-malignancies.
- EOL care was lacking clear organisation in general practice in terms of registering palliative patients and having specific EOL procedures.
- GPs were generally least confident with their skills in terminal medical treatment, e.g. using medicine administered subcutaneously.
Abstract (247 words)

Objective: General practitioners (GPs) are pivotal in end-of-life (EOL) care. This study aimed to assess GP-reported provision of EOL care and to assess associations with GP characteristics.

Design: Population-based questionnaire study.

Setting: Central Denmark Region with approx. 1.3 million inhabitants.

Subjects: All 843 active GPs in the Central Denmark Region were sent a questionnaire by mail.

Main outcome measures: Responses to 18 items concerning four aspects: provision of EOL care to patients with different diagnosis, confidence with being a key worker, organisation of EOL care and EOL skills (medical and psychosocial).

Results: In total, 573 (68%) GPs responded. Of these, 85% often/always offered EOL care to cancer patients, which was twice as often as to patients with non-malignancies (34-40%). Moreover, 76% felt confident about being a key worker, 60% had a proactive approach, and 58% talked to their patients about dying. Only 9% kept a register of patients with EOL needs, and 19% had specific EOL procedures. GP confidence with own EOL skills varied; from 55% feeling confident using terminal medications to 90% feeling confident treating nausea/vomiting. Increasing GP age was associated with increased confidence about being a key worker and provision of EOL care to patients with non-malignancies. In rural areas GPs were more confident about administering medicine subcutaneously than in urban areas.

Conclusion: We found considerable diversity in self-reported EOL care competences. Interventions should focus on increasing GPs’ provision of EOL care to patients with non-malignancies, promoting better EOL care concerning organisation and symptom management.

Key words: Denmark, general practice, palliative care, COPD, heart failure, case management, clinical competence
Introduction

The end of life (EOL) can be defined as ‘the period a patient, the family and health professionals are aware of the life-limiting nature of their illness’ [1]. This time is often characterized by an extensive need for support and comprehensive care. General practitioners (GPs) have a crucial role in providing optimal EOL care as GPs are responsible for at-home care, and their involvement in EOL care is generally highly valued by patients and relatives [2,3]. Several studies have found that most patients prefer to be cared for and die at home [4,5]. Thus, the GPs’ awareness of these patients and their needs, involvement in palliative trajectories, and knowledge about medical treatments must be ensured and maintained.

Cancer patients have been shown to receive EOL care more often than patients non-malignant diseases, although the last group have similar poor prognosis and equal symptom burden [6,7]. However, patients suffering from non-malignant diseases (e.g. heart failure or COPD) have unpredictable disease trajectories which make prognostication of survival time challenging [7]. As these patients are often regularly seen by their GPs as part of chronic disease management, more knowledge is needed if GPs provide EOL care to these patients.

As EOL care often involves many health care professionals, a well-defined key worker is important to ensure cooperation and distribution of tasks [8,9]. Along with a coordinating role, the key worker should take a proactive care approach [8], initiate EOL discussions [10], and be aware of the individual patient’s EOL preferences [11,12]. A revised guideline on palliative care developed by the Danish College of General Practitioners states that GPs are expected to assume the role of key worker [13]. To take on this role, the GPs must have an overview of their relevant patient population to ensure necessary care is provided. Nevertheless, little is known about if GPs’ register these patients and have specific procedures in their organisation to ensure of EOL care to patients.
Previous studies looked into symptom control and home care provided by GPs as a part of EOL care and found room for improvement [9,14-16]. Therefore, training of skills is needed and requested by GPs [16,17]. Knowledge about how the GPs’ perceive their abilities to provide EOL care is a prerequisite for development of successful EOL education in primary care.

Hence, the aim of this study was to assess to which degree GPs report to provide EOL care with regard to patients with different diseases, their confidence with being a key worker, their organisation of EOL care, and their medical and psychosocial EOL care skills. Furthermore, we aimed to analyse if specific characteristics of the GPs and their practices were associated with their perceived abilities to provide EOL care.
Methods

Design
This study was a population-based questionnaire study among all 843 active GPs on 1 of March 2014 in the Central Denmark Region comprising approx. 1.3 million inhabitants.

Setting
The Danish health care system provides free tax-financed access to health care. More than 98% of Danes are registered with a general practice. The GPs are remunerated for their services by the Danish Regions based on a nationally negotiated scheme. GPs are responsible for providing basic palliative care for patients at home listed in their practices [18]. GPs have access to advice from palliative care specialists and can refer to specialist treatment if a patient develops complex palliative needs either physically, psychosocially or spiritually. Specialist palliative care in Denmark is based on outgoing teams, palliative wards, and hospices.

The questionnaire
The 27-item questionnaire with eight predefined themes included both previously used questions and ad hoc items based on experience and existing literature. It was pilot tested among 20 GPs. Eighteen items focused on the four aspects in focus of this study, whereas the remaining 9 items dealt with issues outside the scope of this paper. These four aspects were: 1) GPs’ provision of EOL care to patients with cancer, heart failure and chronic obstructive pulmonary disease (COPD), respectively (items 1-3), 2) GPs’ confidence with being a key worker and performing tasks related to this role (proactive approach, initiating talks about dying and knowing where the patients preferred to die) (items 4-7), 3) organisation of EOL care (having specific EOL procedures and keeping a register of patients with palliative needs) (items 8-9) and 4) GPs’ medical and psychosocial skills (nine different skills ranging from medical to psychosocial elements to embrace the holistic approach to EOL care) (items 10-18) (see Appendix A for wording of the items).
All items were answered on a five-point Likert scale. The questionnaire was sent to all GPs in the Central Denmark Region with a pre-paid postage envelope. If unanswered, a reminder was sent three weeks later. Participation was compensated with 122 DDK (€16).

**The GPs**

Register-based information about the GPs was retrieved from the Central Denmark Region. The data comprised information about the GP’s age, gender, organisation of practices (solo or partnership practice) and list size (number of listed patients). Age and list size were changed into categorical data based on quartiles.

As a proxy for degree of urbanization, the general practices were divided into three groups based on geographic location: municipality with a university hospital (urban areas), municipality with a regional hospital or municipality with no hospital (rural areas).

**Analysis**

Descriptive statistics were used to characterise respondents and non-respondents as well as the GPs’ perception of their EOL care. Estimates were given with 95% confidence intervals (CI). Differences between groups were tested with chi-square test, Mann-Whitney test or Kruskal-Wallis test. Weighted kappa coefficients were used to test for consistency in the GP’s answers for each of the four themes [19]. The coefficients were interpreted as suggested by Landis et al: ‘poor’ (< 0.0), ‘slight’ (0.01–0.20), ‘fair’ (0.21–0.40), ‘moderate’ (0.41–0.60), ‘substantial’ (0.61–0.80) and ‘almost perfect’ (0.81–1.00) [20].

Answers to self-reported confidence in EOL care were dichotomised (agree/strongly agree vs. neither nor/disagree/strongly disagree), and associations with GP characteristics were calculated using a logistic regression model. Five items were chosen to examine the following four aspects of EOL care: 1) whether palliative care would be offered to patients with COPD (representing non-malignant diseases), 2) confidence about being key worker (key worker role),
3) whether the GP had specific EOL procedures (organisation) and 4) confidence with treating pain and administering medicine subcutaneously (i.e. one of the skills with the highest and lowest proportions of reported GP confidence).

The variables used to characterise the GPs (age, gender, list size, organisation and urbanization) were tested for collinearity, but none was found (in all cases, the Pearson’s correlation coefficient was < 0.4). To account for possible cluster effects on practice level robust variance estimation was performed. The level of statistical significance was 5% or less. Stata 13 was used for processing data (www.stata.com).
Results

A total of 573 (68%) GPs participated. Respondents were significantly younger, more often female and more often listed in a group practice compared to non-respondents (Table I).

The GPs’ provision of EOL care to patients with different diagnosis is shown in Table II. The frequency of offering EOL care was considerably higher for cancer patients compared to patients with COPD or heart failure (kappa: 0.21 and 0.17 (data not shown)), whereas the frequency for offering EOL care to patients with COPD and heart failure were fairly similar (kappa: 0.740).

The proportion of GPs who felt confident about being a key worker was 76%. This proportion was larger than the proportions of GPs (56-60%) who agreed to carry out tasks of importance for the role as a key worker, i.e. having a proactive approach, talking to patients about dying and knowing the individual patient’s EOL preferences (Table III). The GPs differed in their agreement with these different elements, which is shown by the weighted kappa coefficient comparing the items on a pairwise basis showing values between 0.21 and 0.41 (data not shown).

Concerning the organisation of EOL care, 9% (95% CI: 6.3; 11.0) of GPs kept a register of their patients with palliative needs, and 19% (95% CI: 15.9; 22.5) had specific EOL procedures.

The majority of GPs felt confident about providing EOL care, but the results also revealed substantial variations (56-89%) across specific palliative skills (Figure 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’ (anticipatory medicine) and administration of medicine subcutaneously), whereas 64% of GPs felt confident about dealing with social issues, and 82% of GPs felt confident about dealing with psychological issues (Figure 1).
Table IV shows associations between different aspects of EOL care and GP characteristics. The oldest GPs reported offering EOL care to COPD patients significantly more often than reported by the youngest GPs. The same trend was seen regarding confidence about being a key worker. No significant associations were found between GP characteristics and organisation of EOL care or EOL care skills with exception from administration of medicine subcutaneously. Female GPs and GPs working in rural areas felt significantly more confident about administering medicine subcutaneously than male GPs and GPs working in urban areas, respectively.
Discussion

Principal findings

GPs were twice as likely to offer EOL care to cancer patients as to patients with non-malignancies. Even though the majority of GPs felt confident about being a key worker, only a small minority of GPs reported to have organised their EOL care. The GPs felt least confident about taking care of social issues and medical treatment in the terminal phase. GP age was positively associated with confidence about being a key worker and increased provision of EOL care to patients with COPD. Gender and degree of urbanization was associated with confidence in administering medicine subcutaneously as more GPs in rural areas and more female GPs felt confident about this task.

Strengths and weaknesses

The strengths of this study were the population-based design, the relatively high response rate and the high-validity register data on GPs. The register-based data made it possible to compare respondents and non-respondents to assess the external validity. As we found differences between respondents and non-respondents in terms of age and gender, the external validity might be impaired. We found age to be associated with confidence about being a key worker, but none of the items illustrating specific elements of being a key worker (e.g. proactive approach) were associated with age. Gender was only associated with confidence about administering medicine subcutaneously. Consequently, the extent of the aforementioned bias that might undermine the external validity seems limited concerning the overall results.

We used a non-validated questionnaire with ad hoc items. The pilot test established apparent face validity of the questions. However, there are well-known problems in palliative research with ambiguous understanding of ‘EOL care’ and ‘palliative care’ [21], which can both be interpreted as terminal treatment of cancer patients and the broader holistic definition encompassing bio-psycho-social factors suggested by WHO [22]. We tried to account for this inherent ambiguity by using the questions on palliative care related to patients with non-
malignant diseases to get an idea of the understanding of palliative care. The data could indicate an ambiguous understanding of palliative care among GPs, where some GPs use the broader holistic approach and others see palliative care as care to cancer patients. Hence, when interpreting the confidence with skills, it might reflect confidence with providing ‘traditional’ care. This might cause a lack of understanding of EOL care provided to patients with non-malignant disease. The results on non-malignancies should, therefore, be interpreted cautiously. Another limitation in terms of content validity is the expression ‘key worker’, which is often used although it is weakly defined. In a palliative context, there is no formal task distribution and hence no clear expectations of a key worker [8,9]. Again, the results should be interpreted with this in mind.

Comparison with other studies

In this study, GPs reported that patients with non-malignant diseases were less likely to receive EOL care. This finding is consistent with other studies, where similar differences in access to palliative care were found between cancer patients and patients with non-malignant diseases [6,7]. To our knowledge, no other study has assessed GPs’ own view of their provision of EOL care to patients with COPD or heart failure. We found similar levels for provision of EOL care to patients with COPD and patients with heart failure. This suggests that GP’s provision of EOL care to patients with non-malignant disease reflects a more general awareness of EOL needs aside from cancer.

In this study, 76% of GPs felt confident about being a key worker in palliative trajectories, which was more than in a previous study from 2012 from the Capital Region of Denmark, where only 57% of GPs felt confident [16]. This could be due to geographical variation. However, in our study, the degree of urbanization was not associated with confidence about being a key worker, but about administering medicine subcutaneously. The difference found between the two studies could also be due to EOL care improvements over time as palliative care has received increased focus in Denmark over the last years [23]. Despite the GPs’ confidence about being a
key worker, a study revealed that many patients and relatives felt that they had to function as
the key worker themselves although they also acknowledged the GP as the ideal key worker [9].
Hence, we need to look into how GPs should assume the role and clarify expectations to the key
worker.

Lack of organisation of EOL care was identified in our study as only few GPs had specific
procedures for EOL care and even less kept register of patients with palliative needs. A national
initiative in the United Kingdom focused on improvement in EOL care by increasing the
proportion of GPs with specific EOL procedures to 39-82% depending on tasks [24]. A review
found that only GPs in Spain and the United Kingdom have a tradition for keeping register of
palliative patients and that this did not necessarily result in conversations about EOL care [25].
So whether keeping a register of patients is affecting clinical practice is uncertain. However, one
could speculate that, without specific EOL procedures or register there might be an increased
risk of overlooking patients with palliative needs and thereby reduced possibilities of taking a
proactive approach. This could be especially important when caring for patients with non-
malignant diseases.

Other studies examined if GP characteristics were associated with confidence in providing
palliative care [16], seeing palliative care as a central part of the GP’s work [26] or involvement
in palliative care [27]. They all found higher age of GPs to be positively associated with
confidence concerning these aspects. In our study, age was only associated with confidence
about being a key worker and increased provision of EOL care to COPD patients. Whether this
higher confidence in being a key worker was actually reflected in the quality of care provided to
patients is uncertain, and this needs further investigation using patient-related outcomes.

More GPs in rural areas felt confident about administering medicine subcutaneously than GPs in
urban areas. In a substantial number of cases, the possibility to give medicine subcutaneously
will be a prerequisite for optimal symptom relief and for the patient to die at home. Additionally,
geographical variation has been found in Denmark with regard to number of home deaths in 2007-2011 [28]. The Capital Region of Denmark had the lowest proportion of home deaths, and the North Denmark Region (more rural area) had the highest proportion [28]. Furthermore, a previous study found that patients in rural areas had more contact to their GP than patients living in urban areas prior to death [29].

Implications

The identified lack of organisation in EOL care calls for introducing a systematic approach in EOL care among GPs. This could be inspired by ideas from the Chronic Care Model (CCM), which effectively has changed the care for chronic diseases in general practice from reactive to proactive [30]. The CCM has a population-based approach to care, where the care is organised for a disease group as well as for the individual patient. In a palliative context, implementing elements from the CCM may support GPs in their key-worker role and enhance a proactive approach. Furthermore, it may be a way to overcome the diagnosis-specific variation in access to EOL care.

None of the GP characteristics were associated with all examined aspects of EOL care, and low agreement between the answers to the different EOL aspects was found. This indicates that confidence and EOL care skills vary considerably among GPs, which is important to consider when addressing GPs in future interventions.

Conclusion

We found diagnosis-specific variations in the GPs’ provision of EOL care as they reported to be more likely to offer EOL care to cancer patients than to patients with non-malignancies. In addition, diversity in the GPs’ self-reported EOL care competencies were found even though most GPs felt confident about being a key worker. A vast majority of GPs reported a lack of EOL care organisation. We identified a need to look further into the importance of geographical
variation and to examine if the association between age and confidence about being a key worker is resulting in better EOL care for the patient.

Future interventions aiming to optimise EOL care in primary care should address the need to increase the provision of EOL care to patients with non-malignancies, facilitate better organisation of EOL care and ensure optimum medical treatment in the terminal phase.

**Ethics approval:** According to the Committee on Health Research Ethics in the Central Denmark Region, this study needed no approval from this committee (file no. 31/2013). The Danish Data Protection Agency (File. no. 2013-41-1965) and the Multi-Practice Committee of the Danish College of General Practitioners (MPU 02-2014) approved the study.

**Financial support:** Danish Cancer Society and the Danish foundation TrygFonden supported the work through the joint grant 'Safety in Palliative Care' [Tryghed i palliative forløb]. The Committee for Quality Improvement and Continuing Medical Education of the Central Denmark Region paid compensation to participating GPs.

**Conflicts of interest:** None.

**Acknowledgement:** We wish to thank all the participating GPs. At the Research Centre for Cancer Diagnosis in Primary Care, Research Unit for General Practice, Aarhus University, Denmark we want to thank data manager Kaare Rud Flarup for setting up the questionnaires and Lone Niedziella for linguistic support. Finally, we want to thank the Committee of Quality and continuing education, Central Denmark Region for support and acknowledgment for the importance of the study.
Legends

Table I: Characteristics of the 843 GPs in the Central Denmark Region divided into respondents and non-respondents.

Table II: Frequency of GP-reported provision of 'end of life care' to three different patient groups (N=573 GPs)

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

Table IV. Associations between GP characteristics and five different questions about EOL care clustered on provider number. The table shows both unadjusted and adjusted analyses; associations are adjusted for all other characteristics. Associations are given in odds ratios (ORs) and the associated p-values (p) are shown. Statistically significant associations are in 'bold'.

Figure 1. Percentage of GPs who reported to feel confident/very confident taking care of nine different elements of EOL care. In all 571 GPs answered these questions.
### Tables and figures

Table I: Characteristics of the 843 GPs in the Central Denmark Region divided into respondents and non-respondents

<table>
<thead>
<tr>
<th></th>
<th>Respondents N=573</th>
<th>Non-respondents N=270</th>
<th>Statistical test of difference¹</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong> (years, median (IQR²))</td>
<td>53.5 (14.5)</td>
<td>55.1 (14.8)</td>
<td><strong>p=0.030</strong>²</td>
</tr>
<tr>
<td><strong>Sex</strong> (n (%))</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>279 (48.7)</td>
<td>155 (57.4)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>294 (51.3)</td>
<td>115 (42.6)</td>
<td><strong>p=0.002</strong>³</td>
</tr>
<tr>
<td><strong>List size</strong> (number, median (IQR'))</td>
<td>1502 (387)</td>
<td>1514 (341)</td>
<td><strong>p=0.110</strong>³</td>
</tr>
<tr>
<td><strong>Organisation of practice</strong> (n (%))</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Solo practice</td>
<td>119 (21.0)</td>
<td>74 (27.5)</td>
<td></td>
</tr>
<tr>
<td>Group practice</td>
<td>447 (79.0)</td>
<td>195 (72.5)</td>
<td><strong>p=0.024</strong>⁴</td>
</tr>
<tr>
<td><strong>Urbanization, municipality with</strong> (n (%))</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University hospital</td>
<td>164 (28.6)</td>
<td>77 (28.5)</td>
<td></td>
</tr>
<tr>
<td>Regional hospital</td>
<td>250 (43.6)</td>
<td>127 (47.0)</td>
<td></td>
</tr>
<tr>
<td>No hospital</td>
<td>158 (27.6)</td>
<td>63 (23.3)</td>
<td><strong>p=0.612</strong>⁵</td>
</tr>
</tbody>
</table>

¹ Statistically significant differences shown in bold text

² IQR: Interquartile range

³ Mann-Whitney test

⁴ Fisher’s exact test

⁵ Kruskal Wallis test
Table II: Frequency of GP-reported provision of 'end of life care’ to three different patient groups (N=573 GPs)

<table>
<thead>
<tr>
<th></th>
<th>Cancer</th>
<th>COPD</th>
<th>Heart failure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% (95% CI)</td>
<td>n</td>
</tr>
<tr>
<td>Always</td>
<td>215</td>
<td>38.7 (34.7; 42.8)</td>
<td>41</td>
</tr>
<tr>
<td>Often</td>
<td>256</td>
<td>46.1 (42.0; 50.3)</td>
<td>182</td>
</tr>
<tr>
<td>Now and then</td>
<td>79</td>
<td>12.6 (9.8; 15.4)</td>
<td>225</td>
</tr>
<tr>
<td>Rarely/never</td>
<td>14</td>
<td>2.5 (1.2; 3.8)</td>
<td>106</td>
</tr>
<tr>
<td>Total(^1)</td>
<td>555</td>
<td>100</td>
<td>554</td>
</tr>
</tbody>
</table>

\(^1\)Missings excluded
Table III: The distribution of answers according to confidence and different elements about being a key worker. (N= 571 GPs).

<table>
<thead>
<tr>
<th></th>
<th>I feel confident about being key worker in palliative trajectories</th>
<th>I am proactive in identifying patients with palliative needs</th>
<th>I take the initiative to talk to my patients about dying</th>
<th>I know where my patients suffering from severe disease want to die</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>n = 141</td>
<td>n = 82</td>
<td>n = 69</td>
<td>n = 50</td>
</tr>
<tr>
<td>% (95% CI)</td>
<td>25.3 (21.7; 28.9)</td>
<td>14.7 (11.7; 17.6)</td>
<td>12.3 (9.6; 15.1)</td>
<td>9.0 (6.6; 11.3)</td>
</tr>
<tr>
<td>Agree</td>
<td>n = 284</td>
<td>n = 252</td>
<td>n = 256</td>
<td>n = 260</td>
</tr>
<tr>
<td>% (95% CI)</td>
<td>51.0 (46.8; 55.2)</td>
<td>45.1 (40.9; 49.2)</td>
<td>45.8 (41.7; 50.0)</td>
<td>46.6 (42.4; 50.7)</td>
</tr>
<tr>
<td>Neither nor</td>
<td>n = 114</td>
<td>n = 170</td>
<td>n = 187</td>
<td>n = 202</td>
</tr>
<tr>
<td>% (95% CI)</td>
<td>20.6 (17.1; 23.8)</td>
<td>30.4 (26.6; 34.2)</td>
<td>33.5 (29.5; 37.4)</td>
<td>36.2 (32.2; 40.2)</td>
</tr>
<tr>
<td>Disagree/ strongly disagree</td>
<td>n = 18</td>
<td>n = 55</td>
<td>n = 47</td>
<td>n = 46</td>
</tr>
<tr>
<td>% (95% CI)</td>
<td>3.2 (1.8; 4.7)</td>
<td>9.8 (6.3; 10.9)</td>
<td>8.4 (6.1; 10.7)</td>
<td>7.5 (5.3; 9.7)</td>
</tr>
<tr>
<td>Total</td>
<td>n = 557</td>
<td>n = 559</td>
<td>n = 559</td>
<td>n = 558</td>
</tr>
<tr>
<td>%</td>
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1Missings excluded
<table>
<thead>
<tr>
<th></th>
<th>OR (95% CI)</th>
<th>p-value</th>
<th>OR (95% CI)</th>
<th>p-value</th>
<th>OR (95% CI)</th>
<th>p-value</th>
<th>OR (95% CI)</th>
<th>p-value</th>
<th>OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>No hospital</td>
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<td>1.000</td>
<td>1.000</td>
<td>1.000</td>
<td>1.000</td>
<td>1.000</td>
<td>1.000</td>
<td>1.000</td>
<td>1.000</td>
<td>1.000</td>
</tr>
<tr>
<td>Regional hospital</td>
<td>1.02</td>
<td>0.204</td>
<td>1.08</td>
<td>0.758</td>
<td>1.08</td>
<td>0.772</td>
<td>1.08</td>
<td>0.772</td>
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<td>0.772</td>
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<tr>
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<td>1.02</td>
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<tr>
<td>Solo稍</td>
<td>1.02</td>
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<td>0.772</td>
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<tr>
<td>Group Organisation</td>
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<td>1.08</td>
<td>0.772</td>
<td>1.08</td>
<td>0.772</td>
</tr>
<tr>
<td>Male</td>
<td>1.07</td>
<td>0.274</td>
<td>1.02</td>
<td>0.427</td>
<td>1.07</td>
<td>0.274</td>
<td>1.02</td>
<td>0.427</td>
<td>1.07</td>
<td>0.274</td>
</tr>
<tr>
<td>Gender</td>
<td>1.07</td>
<td>0.274</td>
<td>1.02</td>
<td>0.427</td>
<td>1.07</td>
<td>0.274</td>
<td>1.02</td>
<td>0.427</td>
<td>1.07</td>
<td>0.274</td>
</tr>
</tbody>
</table>

Statistically significant associations are in bold.

Table IV. Associations between GP characteristics and five different questions about EOL care clustered on provider number. The table shows both unadjusted and adjusted analyses; associations are adjusted for all other characteristics. Associations are given in odd ratios (ORs) and the associated p-values (p) are shown.

EOL care to COPD patients

The key worker

Having specific

EOL procedures

Confidence about being

Confidence with

treatment of pain

Confidence with s.c. medicine

EOL care to COPD patients
Figure 1. Percentage of GPs who reported to feel confident/very confident taking care of nine different elements of EOL care. (N=571 GPs).
References


PAPER III

DEVELOPMENT, MODELLING, AND PILOT TESTING OF A COMPLEX INTERVENTION TO SUPPORT END-OF-LIFE CARE PROVIDED BY DANISH GENERAL PRACTITIONERS

Submitted to ‘BMC Family Practice’
Development, modelling, and pilot testing of a complex intervention to support end-of-life care provided by Danish general practitioners

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Abstract (word count: 346)

**Background:** Most patients in end-of-life with life-threatening diseases prefer to be cared for and die at home. Nevertheless, the majority die in hospitals. GPs have a pivotal role in providing end-of-life care at patients’ home, and their involvement in the palliative trajectory enhances the patient’s possibility to stay at home. The aim of this study was to develop and pilot-test an intervention consisting of continuing medical education (CME) and electronic decision support (EDS) to support end-of-life care in general practice.

**Methods:** We developed an intervention in line with the first phases of the guidelines for complex interventions drawn up by the Medical Research Council. Phase 0 involved evidence-based identification of key barriers to provision of end-of-life care among GPs and of facilitators of change. Phase 1 concerned modelling of two components: CME session and EDS. Phase 2 focused on pilot-testing and intervention assessment by process evaluation.

**Results:** Lack of identification of patients at the end of life and limited palliative knowledge among GPs were identified as barriers in phase 0. The CME session and the EDS were developed in phase 1. The CME session was a four-hour educational meeting performed by GPs and specialists in palliative care. The EDS consisted of two parts: a pop-up window for each patient with palliative needs and a list of all patients with palliative needs in the practice. The pilot testing in phase 2 showed that the CME session was performed as intended and 120 (14%) of the GPs in the region attended. The EDS was integrated in existing electronic records but was shut down early for external reasons; 50 (5%) GPs signed up. The pilot-testing demonstrated a need to strengthen the implementation as attending rate was low in the current set-up.

**Conclusion:** We developed a complex intervention to support GPs in providing end-of-life care. The pilot-test showed general acceptance of the CME sessions. The EDS was shut down early and needs further evaluation before examining the whole intervention in a larger study, where evaluation could be based on patient-related outcomes and impact on end-of-life care.

**Trial registration:** Clinicaltrials.gov (NCT02050256).
Keywords

Continuing medical education, clinical decision support systems, palliative care, end-of-life care, COPD, cancer, general practice, complex intervention, Denmark

Background

The general practitioner (GP) has a pivotal role in palliative care in most western countries. In particular, when the patient is at home, the GP is the key physician [1] and optimally ensures all aspects of continuity in the illness trajectory [2]. The GP often acts as gatekeeper to specialist treatment [3] and thus has the potential to assume a coordinating role for patients with cancer and other life-threatening disease, e.g. chronic obstructive pulmonary disease (COPD) and heart failure.

Most patients with terminal illnesses prefer to be cared for and die at home [4, 5]. Nevertheless, the majority of patients in Denmark and many other western countries end up dying in hospitals [4-6]. Involvement of the GP in the palliative trajectory enhances the patient’s possibility to stay and die at home [7-9]. Therefore, it is crucial to support and optimise the end-of-life care provided by GPs. End-of-life refers to the part of the disease trajectory where people are likely to die within 12 months [10].

No single strategy has so far proven superior in optimising palliative care in general practice [11, 12]. A revised Danish guideline on palliative care in general practice was published in 2014 [13], but a guideline in itself does not change the clinical practice [14]. Continuing medical education (CME) meetings have shown to have a positive effect on changing the GPs’ attitudes concerning palliative care, but they seem to have little impact on the actual provision of care [11]. Electronic decision support (EDS) has improved guideline adherence in other areas (e.g. prescription of antibiotics) and changed clinical outcomes [14-19]. However, a Scottish study showed that GPs were reluctant to use EDS in end-of-life care as the term “palliative” was
hard to apply to electronically identified patients because of the association with death [20]. Still, it is unknown whether a combination of CME and EDS could optimise end-of-life care provision among GPs.

The aim of this study was to develop and pilot-test an intervention consisting of a CME session and EDS to support the end-of-life care in general practice for patients with cancer or COPD.

**Methods**

This study describes the development of a complex intervention in general practice based on the recommendations of the Medical Research Council (MRC) [21, 22]. The MRC framework suggests four phases in the development of a complex intervention. This study focuses on the first three phases; phase 0 focuses on evidence-based identification of barriers to GP provision of end-of-life care and perceived facilitators to change the clinical practice, whereas phases 1 and 2 centre on the modelling and pilot-testing of the intervention, respectively.

**Phase 0: Identification of barriers and facilitators**

Three strategies were used to identify evidence about barriers and facilitators and to adapt these findings to the development of the intervention.

Firstly, two narrative literature searches were performed: one focused on GPs and barriers to end-of-life care, whereas the other focused on facilitators to change clinical care in general practice. The following medical databases were searched: biblioteket.dk, SweMed, PubMed, Embase, Cochrane Library, Cinahl and PsyhInfo. Reference lists were subsequently scrutinised for additional studies, and relevant articles were selected after reading the abstracts.
Secondly, AKW performed three interviews with GPs with a special interest in end-of-life care. The aim of these interviews was to test and culturally adapt the established knowledge on barriers and facilitators from the literature to a Danish clinical setting.

Thirdly, the findings were discussed within the research group (constituted of the authors) drawing on own research and clinical experiences.

*Phase 1: Modelling of the intervention*

By applying a pragmatic approach to the findings in phase 0, the research team selected a number of barriers to address. A multifaceted approach with a tailored intervention was chosen [23, 24] with two components: a CME session and an EDS. Hence, two working groups, including stakeholders with CME experience in general practice, were appointed to assist in designing the components. The group developing the CME session comprised of seven participants: the research group (including an oncologist, two researchers with special interest in general practice and a palliative care specialist), one GP responsible for a regional CME, and two academic coordinators for CMEs targeting GPs in the region.

The EDS working group comprised of two GPs, the research group, and medical and technical staff from the Danish Quality Unit of General Practice (DAK-E). Two successive meetings were held during the development with participation from the GPs engaging in CME, administrative staff from all regions in Denmark, and a member of the research group (AKW). The technical development was carried out by DAK-E. The EDS was made using existing technology to ensure compatibility with all electronic patient record (EPR) systems in Danish general practices [3, 25].

*Phase 2: Pilot-testing and performance assessment*

In the pilot-testing, we adapted the ideas from the MRC guideline [26] and the process evaluation described by Grol et al. [14]. The purpose of process evaluation is to systematically assess the components
in the intervention that could have an impact on the outcome of a pilot study. There is no standard process evaluation, but assessment is suggested to include: 1) the fidelity (i.e. the degree to which the intervention is performed as intended), 2) the quality of the intervention and 3) the context [14, 26]. We assessed the CME session and the EDS separately.

Degree of adherence to the blueprint and the reach of the intervention assessed the fidelity. Adherence to the blueprint examines the extent to which the intervention components were delivered as intended, including whether development of the components succeeded and how well the components were implemented. The implementation plan primarily included sending existing newsletters to all GPs from two different senders. The Quality Unit for Cancer care in general practice in Central Region Denmark invited and reminded the GPs to participate in a CME session (free of charge) in their catchment area. The GPs were informed about the EDS through the regular DAK-E newsletter. Furthermore, the EDS was demonstrated at the CME sessions and briefly presented in a trade journal for Danish GPs [27]. To ensure adherence to blueprint in the CME session and delivery of similar content in each CME session, a test run was performed. All persons engaged in teaching at the CME session were present and received a copy of a detailed plan.

The reach of the intervention was assessed by number of GPs attending the CME session or signed up for the EDS compared to those who did either one or none of them. Background characteristics were retrieved for all GPs in the region to allow comparisons and to clarify if the intervention targeted specific subgroups of GPs.

The attending GPs’ experiences were used to investigate the quality of the intervention. Their experiences were assessed by using a mixed-methods approach carried out by an external evaluation unit in the Central Denmark Region [28]. The evaluation was done using questionnaires and interviews. After each meeting, a questionnaire was handed out to all participating GPs. The questionnaire consisted of seven items concerning benefits of attending the CME session, applied teaching methods, suggestions for
improvements and if/how the CME session might affect their approach to end-of-life care in the future.

Two of the items were answered on a 5-point Likert scale, and the remaining five questions were answered by free text comments.

In addition to the questionnaire, three structured focus group interviews were conducted. Each interview was performed with a group of three GPs and carried out after three of the six CME sessions (i.e. a total of nine interviewed GPs). The interviews focused on three topics: teaching methods, benefits from the CME session and possible improvements. Each interview took approximately 15 minutes.

The short-term impact of the CME session on the GPs’ attitude was assessed by an email sent three months after the CME session to all participating GPs. They were asked: Have you changed anything in your approach to palliative care since the CME? (If yes: then what?; if no: then why not?). The impact of the intervention on provision of end-of-life care was to be fully assessed after one year. The assessment would focus on patient-related outcomes on practice level, e.g. number of terminal declarations (a declaration releasing medical reimbursement for end-of-life care), frequency of prescription of p.r.n. medication used in the terminal phase and number of home deaths; these data were to be retrieved from national registers, and the figures were to be compared before and after the intervention.

To assess participants’ experience with the EDS, a postal questionnaire was planned to be send one year after the implementation to the GPs. The questionnaire contained items about relevance and functionality of the EDS. Furthermore, the specific function of the EDS that identified patients with potential palliative needs (more details are available in the results section), was to be adjusted retrospectively by using register-based data on deceased patients to possibly adjust the criterions for identification. These register-based data were also to be compared to how often the GPs ticked the pop-up window as irrelevant. Finally, as a proxy for usage of the EDS, data on how many times a pop-up was opened by the individual GP were to be retrieved.
Finally, the context of the intervention was assessed by focusing on elements that could facilitate or hamper the effect of the intervention.

The context was the Danish health care system, which is tax financed and provides free access for all residents to health care services. More than 98% of the Danes are registered with a specific general practice, and the GPs are responsible for the health care provision to their listed patients [3]. If symptom relief or problem solving is too complex or not possible in primary care, the GPs can get advice from specialists or refer to specialist treatment [3]. The GPs are remunerated by Danish Regions according to a nationally negotiated scheme. Continuing medical education (CME) was not compulsory for Danish GPs until 2015, but they could receive remuneration for five days a year to cover education expenses and loss of earnings [29]. This study was performed in the spring 2014 in the Central Denmark Region with 843 GPs in 407 practices covering a population of approx. 1.3 million inhabitants.

**Data collection**

Concerning the CME meeting, all participating GPs were registered (provider number, qualified GP/trainee/other, municipality, place of participation) upon arrival at the meeting for evaluation of the implementation of the CME session. GP characteristics (provider number, gender, number of GPs in different areas) were retrieved from the Central Denmark Region to compare participating and non-participating GPs. Data about EDS sign-up were retrieved from the DAK-E database.

The external evaluator, who carried out the evaluation of the CME session, registered the Likert scale answers and collected the answers to the open questions in full wording for each topic and each meeting separately. The interviews were recorded and summarized in themes grouped according to the three overall topics for each of the three interviews.

**Analysis**
Descriptive analysis regarding the attending GPs and their answers to the questionnaires were made. The Likert Scale answers were presented as percentages. The remaining five items with open answers were described qualitatively on the basis of trends and frequency of issues within each topic. Excel® was used for the descriptive statistics.

Results

Phase 0: Identification of barriers and facilitators

One barrier found in the literature review was lack of identification of patients in end-of-life phase, especially for patients with non-malignant diseases [30]. Most clinicians tend to overestimate the remaining life span [31-33], which may compromise timely provision of end-of-life care. Different disease trajectories create different challenges for the GPs in the recognition of end-of-life issues. This could be one reason why patients with COPD tend to get less end-of-life care although their symptoms and prognosis are comparable to those of patients with lung cancer [34-37].

A second barrier was variation in skills and knowledge among GPs concerning the provision of end-of-life care [38-40]. One issue is that some GPs tend to avoid confronting patients and relatives with end-of-life issues, whereas patients and relatives expect the GPs to take such initiatives, to be proactive, and assume the keyworker role in palliative care [40-42].

The facilitators underpinning the effect of the components are listed in Table 1.

Phase 1: Modelling of the intervention

The intervention consisted of a CME session and an EDS, which complemented each other. The CME session was a one-time event allowing time to reflect and engage with colleagues, whereas the EDS continuously provided contextually relevant evidence-based information without interaction with peers.
The framing of the CME session was based on adult learning theory with a problem-based approach to emphasise the relevance to clinical work [24]. The framing paid attention to the independent way in which most GPs work and their preferences for guidance [43, 44]. The content of the CME session was supported by research findings on GPs and end-of-life care, and an updated national guideline on palliative care for general practice published by the Danish College of General Practitioners (Table 2) [13].

The case-based teaching alternated between lectures and discussions. Three short films were produced for the sessions based on research findings to cover the topics in the sessions (table 2). The films were used to facilitate the discussions between the GPs. Engaging with peers, participating actively and sharing own experiences with end-of-life care all aimed at increasing the effect of a CME session [14, 24, 44, 45]. GPs with special interest in end-of-life care were teaching together with a local palliative care specialist. Six CME sessions were held throughout the region based on the catchment area of the specialist palliative care teams.

The final EDS consisted of two connected parts: i) a pop-up window in the patient’s medical record (Figure 1) and ii) a list of patients with end-of-life needs and key elements in their care (Figure 2).

The pop-up window in the patient’s medical record had four functions: an identifier of the patient’s potential end-of-life needs, a reminder to the GP of the patients and actions to take, a provider of medical advice, and a checklist of palliative tasks to consider during the end-of-life trajectory (Figure 1).

To serve as an identifier, the pop-up window was triggered on the first time the GP opened the patient’s medical record if at least one of the following codes were registered in the electronic patient record (EPR): diagnosis of malignancy, palliative diagnosis or COPD with either MRC dyspnoea scale=5 [46], body mass index <18 or FEV1<30 (see Appendix 1 for exact list of diagnosis). The trigger diagnoses were chosen from existing identification tools [47-49] and available patient information in the EPR. The aim was to identify
patients with an estimated remaining life span of 12 months or less. The GP was asked to confirm if the patient was in the end-of-life phase. Additionally, the GP had to indicate the subsequent trigger: either next time the patient would be present in the GP practice or a specific date. This procedure was chosen so that the pop-up could work as a reminder, thereby making it easier for the GP to assume a proactive approach.

The pop-up window provided symptom-specific medical suggestions based on the recommendations from the national clinical guideline [13]. This function of the pop-up was integrated into the medicine module in the EPR to allow quick comparison between medical recommendations and prescribed medications. This easy access to medical advice was made to counterbalance any inadequate medical skills or doubts concerning end-of-life care among the GPs.

The checklist functionality in the pop-up window showed important issues to consider at some point of the palliative trajectory, e.g. making a terminal declaration, prescription of “1-case” box (anticipatory medicine), or registering performance status (Figure 1). The checklist was linked directly to printable forms and assessment tools to minimize the time spent on administration and paper work. The checklists were also linked directly to the corresponding section in the online version of the national clinical guideline [13], where each issue was explained in detail.

The other part of the EDS was the list of the all patients identified by the GP as being in the end-of-life phase; this list was designed to help organise the care and promote a proactive approach. Two entries into the list were possible: Either if the GP filled in anything in the pop-up (apart from ‘irrelevant’) or registered the patient as being in end of life by applying the ICPC diagnosis code “A99” in the EPR. The list showed key elements in end-of-life care (e.g. receiving specialised palliative care, palliative phase, date for next contact) for each patient listed (Figure 2). If the GP was uncertain about a heading, the cursor could be dragged to the heading and an explanation would appear.
The information about key elements was automatically retrieved from data in the pop-up window and shown on the list using colour codes and simple explanations. The list was divided into two tabs to allow different information for different patient groups: one for cancer, one for COPD (Figure 2). Another use of the list was to support the GPs in monitoring the clinical work. Additional suggestions as to how to use the data for this purpose were available for the GPs at the homepage of DAK-E [25].

**Phase 2: Pilot-testing of intervention**

The fidelity was examined for the two components separately. All CME sessions were carried out as planned according to the schedule and the script. Hence, the adherence to the blueprint of the CME session was high.

The EDS was developed as intended, and all the functionalities were integrated in the EPR. However, the development was delayed with regard to the implementation, as it was not ready for use at the time of the CME sessions, which may have decreased the possibility of synergistic effect. Furthermore, the EDS was shut down early due to external legal issues that were unrelated to this project as they concerned data collection from GPs in Denmark in general. The EDS was only running for a short time. The functionality showed high adherence to the blueprint but the implementation had low adherence.

In total, 120 GPs (14.2% of the 843 invited GPs) attended one of the six CME sessions. A relatively higher proportion of female GPs attended in comparison with the gender distribution among all GPs in the Central Denmark Region (Table 3).

Of the 843 invited GPs, 50 GPs (5.9%) signed up for the EDS. We could not retrieve information about the GPs who signed up for the EDS due to the above-mentioned early shutdown. The overall reach of the intervention was low, which compromises the fidelity.

*Quality of CME session*
In total, 115 (95%) GPs answered the questionnaire about the quality of the CME session. The CME session was well received by the attending GPs; overall they reported that they benefitted from participating and gained new knowledge (Figure 3). This was further explored in the interviews as the informants all stated to have benefited from the participation, independent of pre-existing familiarity with palliative care.

The presentation of palliative tools and the instructions on how to complete a request for drug reimbursement due to terminal illness was regarded as useful and appreciated (Figure 3). One of the interviewed GPs stated:

“Then you have something to bring back to the practice and show to the others”.

The teaching style with a mix of lectures and discussion in smaller groups worked well according to the GPs’ questionnaire responses.

The interviewed GPs rated the content of the session to be on a high level and found that the teachers were updated in the field. They also emphasised that teaching by alternating persons and the mix of lectures and discussions with peers worked well. One of the interviewed GPs explained:

“You sit and start thinking, and then it is nice to have the opportunity to share the thoughts with people around you”.

A potential improvement of the CME session was to give higher priority to the practical skills. Other suggestions were to extend the course duration to allow more discussions, work longer with the cases, and ensure more time for the palliative specialist to interact.

Three areas relating to end-of-life care also emerged as new to the GPs: they obtained a broader understanding of end-of-life care and realized that it also embraces other patient groups than cancer
patients, increased their awareness of their proactive role, and directed more attention towards patients with potential palliative needs.

As one of the interviewed GPs stated:

“We might need to enter the playing field and not wait for the patients to come to us, right?”

Furthermore, the importance of using a more systematic approach and organising end-of-life care at practice level was highlighted. The CME session succeeded in addressing the main barriers. Yet, several issues that were raised at the CME sessions (e.g. awareness of the relatives’ needs and the importance of symptom screening) were not mentioned in either the questionnaire of the interviews as new areas of awareness.

**Impact of CME session**

In total, 29 (25%) GPs participated in the three-month evaluation. A fourth of the GPs stated specifically that they had adapted a more proactive approach to end-of-life care. Furthermore, they reported to have obtained increased awareness about palliative needs among patients with non-malignant diseases. Three of the 29 GPs (10%) stated that they had no patients with palliative needs after the CME session.

**Impact of EDS**

Due to the early shutdown of the EDS, we could not evaluate its impact. As the EDS was demonstrated on the CME session, many GPs made unsolicited positive comments about the EDS in both the questionnaire and the interview. The GPs stated that they looked forward to using the EDS, and their immediate impression was that it would be a helpful tool:

“I will look forward to using the EDS which is on its way – it seems very applicable”.
**The context of the intervention**

One specific event could in the context have hampered the effect. At the time of the implementation of the intervention, there was a nationwide disagreement between the GPs and Danish Regions. This might have made some GPs reluctant to participate as the regional administration, i.e. the Central Denmark Region, was involved in establishing the CME session. This connection was unintended as the staffs from the Central Denmark Region were involved exclusively to ensure high quality of the CME. The CME session was approved by the Public Health and Quality Improvement in the Central Denmark Region to allow remuneration of the attending GPs.

**Discussion**

**Main findings**

It was possible to model the intervention to address identified barriers to end-of-life care in general practice and use evidence-based facilitators to enhance the effect of the intervention. Although the participation rate was only 15%, the pilot-testing showed that the CME session was well received among the attending GPs. The session had an immediate impact on the GPs and addressed the identified barriers, which suggests high quality. Evaluation of the EDS could not be performed due to early shutdown. The process evaluation of the pilot-test revealed a need to look further into how the intervention in full scale could be designed to reach more GPs.

**Strengths and limitations**

One of the strengths of the study was the systematic development of the complex intervention in accordance with the MRC guideline [21], which facilitated integration of evaluation in the design. This allowed analyses of the different steps and elements of the complex intervention and enabled us to investigate not only if the intervention worked, but also how it worked. This approach generally improves the applicability of tailored interventions to other settings as it makes it easier to adapt relevant components. However, a limitation of using the guideline was the lack of standard process evaluation [14].
A strength of the study was the inclusion of stakeholders from an early stage of the modelling of the intervention; this increased the applicability and facilitated the implementation. The reach of the intervention was evaluated using register data, which allowed comparisons between attending GPs and all GPs in the region. The external evaluation carried out in the CME session reduced the risk of bias, especially with regard to the interviews after the sessions. The use of questionnaires for evaluation of the CME allowed us to assess both the immediate and the three-month self-perceived effect of the CME session on the GPs. However, the low participation in the follow-up compromised the generalisability of the three-month effect.

A major limitation of this study was the early shutdown of the EDS, which prevented evaluation of the reach, the participants’ experience, and the quality and impact of the EDS. Another limitation of the study was the low attendance rate at the CME sessions and the lack of possibility to examine attendance further in the current design.

Comparison with other studies

One barrier we intended to address in both the CME session and the EDS was identification of patients with palliative needs [31, 50, 51]. A Dutch intervention by Thoosen et al. found that patients with palliative needs identified by their GP had more contact with their GP, less hospital admissions, and were more likely to die at home than not identified patients [52]. These findings underline the importance of the GP’s awareness and identification of patients with palliative needs. In the study by Thoosen et al., the GPs had to apply an identification tool (RADPAC) by going through their patients manually. Hence, the identification was still dependent on the GP’s awareness of palliative needs. Mason et al. made a computerised tool to identify patients with deteriorating health due to advanced conditions [20]. They found that some GPs were reluctant to register the computer-identified patients as “palliative” due to associations to death. The
resistance against using the term “palliative care” earlier in the disease trajectory compromised the effect of the tool. This underlines the need for a change in attitude alongside the implementation of an EDS.

The attendance rate in the CME session was low in our study compared to other Danish studies. A disease management programme in 2010 in the same region had an attendance rate of 69% [53]. However, these GPs were remunerated for participating, and the programme formed part of a regional initiative aiming to prioritise and optimise chronic care management. Another Danish study with 1-hour CME sessions in 2012 focusing on lung cancer diagnosis had an attendance rate of 49% [54]. The low attendance rate in this study could have several explanations: lack of interest, no need for education in end-of-life care, bad timing of the intervention, or poor implementation of the CME session.

The low attendance rate in our study is unlikely to reflect a lack of need for education in end-of-life care. A prior Danish study identified a need of improvement of palliative care skills and a lack of confidence in providing end-of-life care among GPs [30, 38]. Furthermore, a British study reported that most GPs wanted training focusing on different care issues when asked about their educational preferences in palliative care [39]. The timing of the intervention may have adversely affected the attendance rate due to the disagreement between Danish Regions and the GPs.

Clinical implications and future perspectives

The increased longevity in the population may result in rising incidence of cancer and more terminally ill patients with non-malignant disease. Most of these patients wish to be cared for at home. Hence, there is a growing need for GPs who are skilled and confident in providing palliative care.

The evaluation of the intervention revealed increased awareness among GPs of potential palliative needs in other patient groups than cancer patients. The findings also suggest that the GPs should take a more proactive role and organise the care. Although the participating GPs suggested higher prioritisation of
demonstration of practical skills in the CME, we recommend maintaining the current balance between practice and theory. The reason for this is increased awareness and broadening of understanding of end-of-life care together with improved skills are prerequisites for optimising care, which would benefit all groups of patients.

As the CME session was well received by the GPs and addressed the main barriers to end-of-life care, it is ready to be used in a full-scale study assessing the effect of the intervention on patient-related outcomes. However, the EDS needs to be evaluated before used in full-scale study. Furthermore, it could be beneficial to assess the implementation itself, as the participation rate was low in the set-up tested in this study.

**Conclusion**

A complex intervention consisting of CME sessions and EDS to aid GPs provide better end-of-life care was developed using MRC guidelines and current evidence. The evaluation of the pilot-test showed overall appreciation of the CME sessions, which addressed identified barriers to providing care. The EDS was shut down early and needs further evaluation before examining the whole intervention in a larger study, where evaluation could be based on patient-related outcomes and the impact on end-of-life care.

**List of abbreviations**

AKW: Anna Kirstine Winthereik (part of research team)
CME: Continuing Medical Education
COPD: Chronic Obstructive Pulmonary Disease
EDS: Electronic decision support
EPR: Electronic patient records
FEV1: Forced Expiratory Volume in 1 second
ICD-10: International Classification of Diseases, version 10
ICPC: International Classification of Primary Care
GP(s): General practitioner(s)

MRC: Medical Research Council

**Declarations**

**Ethics**

According to the Committee on Health Research Ethics of the Central Denmark Region, the Danish Act on Research Ethics Review of Health Research Projects does not apply to this project (file no. 31/201). The study was approved by the Danish Data Protection Agency (J.no. 2013-41-1965) and was registered in clinicaltrials.gov (NCT02050256).

**Consent for publication**

Not applicable

**Availability of data and materials**

The datasets generated and analysed during the current study are not publicly available due restriction from the Danish Data Protection Agency but are available from the corresponding author on reasonable request.

**Competing interest**

The authors declare that they have no competing interests

**Funding**

The Danish Cancer Society and the Danish foundation TrygFonden supported the study through the joint grant ‘Safety in Palliative Care’ [Tryghed i palliative forløb]. The funding body did not have a role in either the design of the study, the data collection, analysis and interpretation of data nor in the writing of the manuscript.
Authors’ contributions
AKW, MAN, AB, and PV conceived the idea of the study. All authors were involved in the design of study.
AKW took an active part in the shaping of the EDS and the CME session. MAN, AB, and PV took part in the design of the CME session. AKW acquired, analysed and interpreted the data, and drafted the manuscript.
MAN, AB, and PV took part in the interpretation of the data and revised the manuscript. All authors have read and approved the final manuscript.

Acknowledgements
We wish to thank all the participating GPs in Central Denmark Region. We want to thank the Quality Unit for Cancer Care in general practice for their help with designing and carrying out the CME session, especially GP Rikke Pilegaard Hansen, PhD and academic coordinator Gry Stie. Furthermore, we wish to thank the Danish Quality Unit of General Practice for making the EDS, especially GP Berit Lassen, the IT developers, and the administrative staff. Additionally, we want to thank data manager Kaare Rud Flarup, Research Centre for Cancer Diagnosis in Primary Care, Research Unit for General Practice, Aarhus University, Denmark for setting up the questionnaires and Lone Niedziella for linguistic support. Finally, we wish to thank Emil Christian Gram for graphical assistance.

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Peter Vedsted (PV), professor, PhD, medical doctor, Research Unit for General Practice, Aarhus University, Denmark, p.vedsted@alm.au.dk.
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Accessed 14 December 2015
Table 1: Facilitators supporting the effect of a CME session

<table>
<thead>
<tr>
<th>Facilitator</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case-based teaching</td>
<td>[23]</td>
</tr>
<tr>
<td>Guidance rather than orders</td>
<td>[43]</td>
</tr>
<tr>
<td>Educational meetings in small groups</td>
<td>[13]</td>
</tr>
<tr>
<td>Engaging with peers</td>
<td>[13, 23, 43, 44]</td>
</tr>
<tr>
<td>Active participation</td>
<td>[13, 23, 43, 44]</td>
</tr>
<tr>
<td>Sharing experiences with end-of-life care</td>
<td>[13, 23, 43, 44]</td>
</tr>
<tr>
<td>Involving opinion leaders</td>
<td>[13]</td>
</tr>
<tr>
<td>Encounters with specialist</td>
<td>[13, 43]</td>
</tr>
<tr>
<td>Time</td>
<td>Curriculum covered in each session</td>
</tr>
<tr>
<td>-----------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 4.30-5.10 pm    | **What is palliative care?**  
- Definition and changes in the understanding of palliative care. Focus on end-of-life care  
- Disease trajectories and the challenges in identifying when end-of-life care is needed  
- Discussion of patient case: (short film)                                                                 |
| 5.25–6.00 pm    | **What are the patients' palliative needs?**  
- Results from a Danish survey among palliative patients  
- Discussion of two patient cases (short films)                                                                 |
| 6.30–6.45 pm    | **Presentation of the local palliative team by the palliative physician**                                                                                           |
| 6.45–7.35 pm    | **Medical skills and practicalities**  
- Prescription of just-in-case\(^1\) box, terminal declaration\(^2\), use of EDS, etc.                                                                     |
| 7.45–8.00 pm    | **Local support to patients and relatives**  
- Which alternatives does the GP have? Who else can help and support?                                                                                          |

\(^1\) Anticipatory medicine  
\(^2\) Declaration releasing medical reimbursement for end-of-life care
Table 3. Characteristics of the CME-attending GPs and all GPs in the Central Denmark Region

<table>
<thead>
<tr>
<th></th>
<th>Participants¹</th>
<th>GPs in the Central Denmark Region</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GPs</strong></td>
<td>120</td>
<td>843 (100.0)</td>
</tr>
<tr>
<td><strong>Age, (median iqr), years</strong></td>
<td>54 (15)</td>
<td>54 (14.4)</td>
</tr>
<tr>
<td><strong>Gender, (n(%))</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>43 (35.8)</td>
<td>434 (51.5)</td>
</tr>
<tr>
<td>Female</td>
<td>77 (64.2)</td>
<td>409 (48.5)</td>
</tr>
<tr>
<td><strong>Place of meeting, (n, (%))</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Viborg</td>
<td>8 (6.6)</td>
<td>84 (10.0)</td>
</tr>
<tr>
<td>Horsens</td>
<td>18 (15.0)</td>
<td>136 (16.1)</td>
</tr>
<tr>
<td>Silkeborg</td>
<td>15 (12.5)</td>
<td>67 (8.0)</td>
</tr>
<tr>
<td>Herning</td>
<td>25 (20.8)</td>
<td>185 (22.0)</td>
</tr>
<tr>
<td>Randers</td>
<td>25 (20.8)</td>
<td>144 (17.1)</td>
</tr>
<tr>
<td>Aarhus</td>
<td>29 (24.2)</td>
<td>223 (26.5)</td>
</tr>
<tr>
<td>Unknown</td>
<td>-</td>
<td>4 (0.5)</td>
</tr>
</tbody>
</table>

¹ Additional 19 persons participated: 15 GP trainees, 3 nurses, or 2 other health care persons
**Figure 1. The EDS pop-up window generated in the medical records to be filled in by GP**

1: Directly linked to the EORTC QLQ-C15-PAL [55] in the palliative guideline [13]: ready to print and hand out to the patient.

2: ECOG Performance Status [56].

* The information is automatically transferred to the palliative list.
Figure 2. The list of all patients with palliative needs in the practice divided into patients with cancer and COPD, respectively.

<table>
<thead>
<tr>
<th>Cancer patients</th>
<th>Patients with COPD</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>CPR-number</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Term. decl.</th>
<th>Perf. status</th>
<th>C diag</th>
<th>P diag</th>
<th>Cancer diagnosis</th>
<th>GP</th>
<th>Staff</th>
<th>Specialist care</th>
<th>Latest pop-up</th>
<th>Next pop-up</th>
<th>Last consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steven Lassen</td>
<td>100001-xxxx</td>
<td>60</td>
<td>CA1</td>
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<td></td>
<td></td>
<td></td>
<td>16/02/2012</td>
<td>d</td>
<td>n/a</td>
<td></td>
<td>16/02/2014</td>
<td>16/02/2014</td>
<td>16/02/2014</td>
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<tr>
<td>Annenr Bach</td>
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<td>Frank Thygesen</td>
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<td>29/10/2013</td>
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<td>d</td>
<td>n/a</td>
<td></td>
<td>1/10/2013</td>
<td>1/10/2013</td>
<td>1/10/2013</td>
</tr>
<tr>
<td>Hanne Petersen</td>
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<td>CA1</td>
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<td></td>
<td></td>
<td>1/10/2012</td>
<td>d</td>
<td>n/a</td>
<td></td>
<td>1/10/2013</td>
<td>1/10/2013</td>
<td>1/10/2013</td>
</tr>
<tr>
<td>Ole Madsen</td>
<td>200001-xxxx</td>
<td>78</td>
<td>CA1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>1/10/2012</td>
<td>d</td>
<td>n/a</td>
<td></td>
<td>1/10/2013</td>
<td>1/10/2013</td>
<td>1/10/2013</td>
</tr>
<tr>
<td>Peter Hansen</td>
<td>100001-xxxx</td>
<td>75</td>
<td>CA1</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td>29/10/2013</td>
<td>d</td>
<td>n/a</td>
<td></td>
<td>29/10/2013</td>
<td>29/10/2013</td>
<td>29/10/2013</td>
</tr>
<tr>
<td>Lone Petersen</td>
<td>100001-xxxx</td>
<td>82</td>
<td>CA1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>1/10/2013</td>
<td>d</td>
<td>n/a</td>
<td></td>
<td>1/10/2013</td>
<td>1/10/2013</td>
<td>1/10/2013</td>
</tr>
<tr>
<td>Henrik Petersen</td>
<td>200001-xxxx</td>
<td>78</td>
<td>CA1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>29/10/2013</td>
<td>d</td>
<td>n/a</td>
<td></td>
<td>29/10/2013</td>
<td>29/10/2013</td>
<td>29/10/2013</td>
</tr>
</tbody>
</table>

The tab for COPD contains additional information on smoking status, number of exacerbations within the last year and MRC breathlessness score. All information shown in the figure is made up for the figure and not based on real data.

CPR number: Personal identification number allocated to every Danish citizen.

Diagnosis: The cancer diagnosis (ICD 10). When the cursor marks the diagnosis, it is written in words.

Term. decl: Terminal declaration. Data retrieved from the pop-up window.

Perf. Status: ECOG performance status [56]. Data retrieved from the pop-up window.

C and P diag: Comorbidities and psychiatric comorbidities; a dot means that the patient is registered with comorbidity (written in text when the cursor is dragged to the dot). Data retrieved automatically from the EPR.

GP/staff: The patient’s contact GP/staff in the practice(s). Data retrieved from the pop-up window.

Specialist care: The patient receives specialist palliative care. Data retrieved from the pop-up window.

Latest pop-up window: A marker indicates that a note has been left by the GP/staff in the pop-up window (can be read when the cursor is dragged to the dot).
Figure 3. *The distribution (% of questionnaires (n=115)) of GPs’ self-reported usefulness of attending the CME and the demonstrated tools.*

Made by the Committee for Quality Improvement and Continuing Medical Education in the Central Denmark Region as a part of the evaluation of the CME sessions [57]
ICPC [58, 59] and ICD-10 [60] codes that prompted the pop-up window in the patient’s medical record were retrieved from discharge summaries (ICD-10) or the GP’s medical record (ICPC):

ICPC codes:

Malignancies:
A79, B72, B73, B74, D74, D75, D76, D77, L71, N74, R84, R85, S77, T71, U75, U76, U77, W72, X75, X76, X77, Y77, Y78

Chronic obstructive pulmonary disease:
R95: MRC5, BMI<18 or FEV1<30 is registered in the patient’s medical record.
A99: One of the above ICPC codes is listed.

ICD-10 codes:

DZ515, DC76, DC77, DC78, DC79, DC80 (all sub-codes are included)
APPENDIX I:

QUESTIONNAIRE, COVER LETTER AND REMINDER USED IN PAPER II
# Palliation i almen praksis

## Dato for besvarelse:

<table>
<thead>
<tr>
<th>Dag</th>
<th>Måned</th>
<th>Årstal</th>
</tr>
</thead>
</table>

## 1. Dit forhold til palliation generelt

<table>
<thead>
<tr>
<th>Hvor enig er du i følgende:</th>
<th>Helt enig</th>
<th>Enig</th>
<th>Hverken enig eller uenig</th>
<th>Uenig</th>
<th>Helt uenig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeg føler mig fortrolig med at kunne være den gennemgående sundhedsperson i palliative forløb</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

## 2. Dine palliative færdigheder

<table>
<thead>
<tr>
<th>Sammenlignet med gennemsnittet for dine kolleger, hvordan vurderer du så dine palliative færdigheder?</th>
<th>Noget over gennemsnit for kolleger</th>
<th>Lidt over gennemsnit for kolleger</th>
<th>Som gennemsnit for kolleger</th>
<th>Lidt under gennemsnit for kolleger</th>
<th>Noget under gennemsnit for kolleger</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

## 3. Palliativ behandling

<table>
<thead>
<tr>
<th>I den basale palliative behandling er jeg helt fortrolig med:</th>
<th>Helt enig</th>
<th>Enig</th>
<th>Hverken enig eller uenig</th>
<th>Uenig</th>
<th>Helt uenig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behandling af smerter</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Behandling af kvalme/opkastning</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Behandling af forstoppelse</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Behandling af åndenød</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Subkutan medicinadministration</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Anvendelse af tryghedskassen</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At tage hånd om patientens psykiske tilstand</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At tage hånd om patientens sociale situation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At tage hånd om de pårørende og deres behov</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

## 4. Planlægning af patientens sidste tid

<table>
<thead>
<tr>
<th>Hvor enig er du i følgende:</th>
<th>Helt enig</th>
<th>Enig</th>
<th>Hverken enig eller uenig</th>
<th>Uenig</th>
<th>Helt uenig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeg opsøger aktivt mine patienter med palliative behov</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg tager typisk initiativ overfor patienten til, at vi får talt om det at skulle dø</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg ved, hvor mine alvorligt syge patienter ønsker at dø</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg inddrager aktivt hjemmeplejen i planlægningen af patientens sidste tid</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg inddrager aktivt de pårørende i planlægningen af patientens sidste tid</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Palliation i almen praksis

5. Palliative patienter i praksis

<table>
<thead>
<tr>
<th>Hvor hyppigt tilbyder du basal palliativ behandling til følgende patientgrupper i din praksis:</th>
<th>Altid</th>
<th>Ofte</th>
<th>Sommetider</th>
<th>Sjældent</th>
<th>Aldrig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patienter med kræft</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patienter med kronisk lungesygdom</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patienter med hjertesvigt</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patienter med neurologiske lidelser</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Patienter med demens</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

6. Organisering

<table>
<thead>
<tr>
<th>Hvor enig er du i følgende:</th>
<th>Helt enig</th>
<th>Enig</th>
<th>Hverken enig eller uenig</th>
<th>Uenig</th>
<th>Helt uenig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeg er telefonisk tilgængelig for mine palliative patienter udenfor normal arbejdstid</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Det er svært at afsætte tid i min hverdag til patienter med palliative behov</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg/vi har en overordnet fast procedure omkring palliative forløb i min/vores praksis</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Der er god mulighed for at få råd og vejledning fra det palliative team om palliative forløb</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Der er god mulighed for at samarbejde med det palliative team om palliative forløb</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Der er god mulighed for at samarbejde med hjemmeplejen om palliative forløb</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

7. Overblik

Har du/I en liste over alle dine/jeres palliative patienter? ☐ Ja ☐ Nej

8. Barrierer

Hvad er efter din mening de tre vigtigste barrierer for at udføre optimalt palliativt arbejde i almen praksis? (Skriv venligst tydeligt)

1. ____________________________ ☐ ☐

2. ____________________________ ☐ ☐

3. ____________________________ ☐ ☐

Ønsker du honorering for besvarelsen? ☐ Ja ☐ Nej

Spørgeskemaet returneres i vedlagte svarkuvert

Tusind tak for din besvarelse af spørgeskemaet
Invitation til spørgeskemaundersøgelse om den palliative indsats

Kære kollega


Du inviteres hermed til at deltage i en undersøgelse af praktsiserende lægers palliative arbejde, og vi vil bede dig udfylde vedlagte korte spørgeskema og returnere det i vedlagte frankerede svarkuvert. Besvarelsen af spørgeskemaet vil blive honoreret med et beløb, der svarer til ét modul (122,57 kr.).

Undersøgelsen er en del af et større initiativ med fokus på den basale palliative indsats. Alle data opbevares fortroligt og behandles i anonymiseret form. Deltagelse i projektet anbefales af DSAM’s og PLO’s Multipraksisudvalg.

Palliation – en særlig indsats i regionen

Den palliative indsats vil også blive styrket via særlige indsatser fra DAK-E og Region Midtjylland. Alle praktiserende læger i regionen vil i de kommende måneder blive inviteret til efteruddannelse om palliation. Kurserne er arrangeret af Cancer i Praksis (CiP), efteruddannelsesvejlederne og praksiskonsulenterne i regionen og er godkendt af Lægeforeningens efteruddannelsesfond. Du kan læse mere på www.praksis.dk ved at søge på ”etteruddannelse om god palliativ indsats”.

Du hører fra os igen

Hvis vi ikke har hørt fra dig om tre uger, vil vi tillade os at sende en påmindelse. Du vil modtage det samme spørgeskema igen om et år, så vi kan se, om der er sket en udvikling på området.

Vi håber, at du vil være med. En høj deltagelse er afgørende for undersøgelsens validitet og konklusioner.

Hvis du har spørgsmål, er du meget velkommen til at kontakte læge og projektleder Anna Kirstine Winthereik: tlf. 22 45 70 97 eller akwi@ki.au.dk.

Anna K. Winthereik
Anders Bonde Jensen
Mette Asbjørn Neergaard
Peter Vedsted
Ph.d.-studerende, læge
Professor, ph.d., overlæge,
Ph.d., overlæge
Professor, ph.d., læge,
Onkologisk Afd., AUH
Onkologisk Afd., AUH
Det Palliative Team, AUH
Forskningsenheden for Almen Praksis, Aarhus Universitet
Kære Kollega,

For nogle uger siden sendte vi dig et spørgeskema om alment praktiserende lægers palliative indsats.

Da vi endnu ikke har modtaget svar fra dig, tillader vi os at mindes dig om undersøgelsen ved at gendanne spørgeskemaet. Deltagelse i projektet er anbefalet af PLO's og DSAM's Udvalg vedrørende Multipraksisundersøgelser.

Formålet med undersøgelsen er at opnå bedre viden om praktiserende lægers palliative arbejde for at kunne optimere den basale palliative behandling til gavn for alle uhelbredeligt syge patienter.

Undersøgelsens konklusion er yderst afhængig af en høj deltagelse.

**Du deltager i undersøgelsen ved at udfylde og returnere det vedlagte kortfattede spørgeskema.** Du har mulighed for at blive honoreret med 1 modul (kr. 122,57) for besvarelsen (angiv venligst dette nederst på spørgeskemaet).

**Spørgeskemaet returneres i vedlagte svarkuvert.**

Ved eventuelle spørgsmål er du meget velkommen til at kontakte læge Anna Kirstine Winthereik (tlf. 22 45 70 97 eller akwi@ki.au.dk).

På forhånd tak.

På projektgruppens vegne:

Anna Kirstine Winthereik  
læge, ph.d.-studerende,  
Onkologisk afd., AUH

Anders Bonde Jensen  
Professor, overlæge,  
Onkologisk Afd., AUH

Mette Asbjørn Neergaard  
Overlæge, ph.d.  
Det Palliative Team, AUH

Peter Vedsted  
Professor, ph.d., læge,  
Forskningsenheden for Almen Praksis, Aarhus Universitet
APPENDIX II:
THE SCRIPT OF THE CME SESSION
Drejebogsudkast til efteruddannelse i palliation for læger i almen praksis

Udarbejdet af Cancer i Praksis (CiP) i samarbejde med Center for forskning i cancerdiagnostik i praksis (CaP), Forskningsenheden for Almen Praksis, Aarhus Universitet, Efteruddannelsesvejlederne i Almen Praksis og Det Palliative team/Onkologisk Afdeling D, Aarhus Universitetshospital
Udarbejdet af:

Gry Stie, Faglig koordinator, Cancer i Praksis
Rikke Pilegaard Hansen, Praktiserende læge, ph.d., Lægekonsulent
Tommy Stoltz Olsen, Praktiserende læge, Efteruddannelsesvejleder
Anna Winthereik, Læge, ph.d.-studerende tilknyttet Onkologisk Afdeling D, Aarhus Universitetshospital
Mette Asbjørn Neergaard, Overlæge, ph.d., Det Palliative team, Onkologisk Afdeling D, Aarhus Universitetshospital

I samarbejde med:
Peter Vedsted, Professor, Ph.d., Forskningsleder, Center for Forskning i Cancerdiagnostik i Praksis - CaP, Forskningsenheden for Almen Praksis, Aarhus Universitet
Anders Bonde Jensen, Professor, Overlæge, Onkologisk Afdeling D, Aarhus Universitetshospital
Dette er en drejebog for efteruddannelse i palliation for praktiserende læger. Formålet med drejebogen er at skabe en ramme for indsatsen. Indsatsen vil dels rette sig mod kræftpatienter, som udgør den største gruppe af palliative patienter, men også mod patienter med non-maligne livstruende sygdomme (som eksempelvis kronisk obstruktiv lungetideladelse (KOL)).

Drejebogen skal tilpasses lokale forhold, så der tages hensyn til lokale/regionale forhold i relation til temaer, undervisere og afvikling. Indholdet er som beskrevet i Kræftplan III målrettet lægen i almen praksis.

Fokus i efteruddannelsesforløbet er følgende emner;

– Hvad er palliation i Almen Praksis
– Praktiserende læges rolle i den sen-palliative fase
  o Herunder barrierer i det palliative arbejde
– Identifikation af patientgruppen i praksis
– Redskaber og metoder til gode palliative forløb

**De overordnede rammer for efteruddannelsesforløbet er følgende:**

- Efteruddannelsesaktiviteten gennemføres som et fyraftensmøde på cirka 3 timer og afvikles metodisk som en lærende konferencemodel (stormøder med interaktiv dynamik og mødefacilitatorer). Der forventes at blive ca. 7 møder.
  o Anna Winthereik randomiserer lægerne i interventions- og kontrolgrupper, og derved identificeres de ca. 7 interventions-grupper, som skal indbydes til efteruddannelsen.
- Efteruddannelsestilbuddet kan med fordel planlægges omkring den regionale samarbejdsstruktur omkring hospitalerne og de palliative teams.
- Efteruddannelsestilbuddet planlægges og gennemføres af CiP, Region Midtjylland i samarbejde med konsulenter fra almen praksis, Forskningsenheden for Almen Praksis, Aarhus Universitet og Det palliative Team/Onkologisk afdeling, Aarhus Universitetshospital. Regionale og nationale Sundhedsplaner, aftaler om samarbejde og DSAMs vejledning om palliation (ny forventes i start 2014) vil blive integreret i efteruddannelsesforløbet.
Deltagerne inviteres af et partnerskab mellem Region Midtjylland, konsulenter fra almen praksis, Forskningsenheden for Almen Praksis, Aarhus Universitet, Onkologisk afdeling samt Det palliative team, Aarhus Universitetshospital.

Forløbet vil blive forhåndsgodkendt ved efteruddannelsesfonden, så lægerne kan søge om personlige efteruddannelsesmidler til refusion af eventuelle transportudgifter.

De konkrete rammer for efteruddannelsesforløbet er følgende:

- Deltagerkredsen deles op i interventions- og kontrolgruppe
- Processen ledes af en/flore inspirerende facilitator(er)(etteruddannelsesvejleder/praksiskonsulent), der styrer aftenens forløb og sikrer aktiv inddragelse af deltagerne. “Guldornene” ligger også blandt deltagerne, og det skal vi have i spil, så erfaringer kan deles.
- Der laves små undervisningsfilm (interviews af patient og pårørende (spilles af skuespillere)). Patient- og pårørendehistorier baseres på viden om patient og pårørendes ønsker i palliationsforløb (forskningsresultater – evt. henvisning hertil).
- Så vidt muligt deltager lokale undervisere: Lokale praktiserende læger med særlig erfaring med organisering af palliative forløb og læger fra de lokale palliative teams.
- Der holdes planlægningsmøde med alle oplægsholdere, hvor oplæggene afstemmes. Oplægsholderne vil blive informeret om forventningerne til oplæggenes karakter (aktive oplæg - og powerpoints kun til relevante detaljer). Alle oplæg skal supplieres med en refleksionsopgave, så lægernes egen adfærd og erfaringer bringes i spil.
- Pausen midt i efteruddannelsesaktiviteten er struktureret som cafémøde hvor man kan netværke med kollegaer eller som aktiv markedsplads, hvor man kan tale med oplægsholdere, regionale konsulenter (f.eks. it-konsulenter m.fl.) Her må lokale forhold og muligheder afgøre formen. Det afgørende er netværk blandt kollegaer og mulighed for at drøfte indholdet med andre end dem, man sidder til bords med.
- Evaluering
I Anna Winthereiks ph.d. indgår en evaluering af ændringer på lægernes palliative indsats (måles blandt andet på patientniveau).

Derudover gennemfører CFK - Folkesundhed og Kvalitetsudvikling på vegne af CIP en evaluering af selve undervisningsformen.

Oversigt over temaer i efteruddannelsen

1. **Hvad er palliation?** (Hvad er palliation, og hvad er praktiserendes læges rolle i palliative forløb?)
   - Filmcase 1 anvendes før opsamling i introduktionsdelen (Pårørende til afdød KOL-patient)

2. **Hvad efterspørger patienterne** (Teori og viden om palliation og barrierer for god palliation)
   - Filmcase 2 (Pårørende til afdød cancer patient: Proaktiv læge)
   - Filmcase 3 (Cancerpatient med kompliceret forløb)

3. **Praktiske tag-med-hjem-ting** (Redskaber og håndtering af barrierer)

4. **Evaluering af efteruddannelse**

   *Noter til Tema 3
   (Teksten kunne ikke være i skemaet, derfor står den her, skal indarbejdes i oplæg.)
   - Idé katalog om tilrettelæggelse af palliative forløb i praksis
     - Flowchart fra Esben vedr. organisering af det palliative forløb i praksis
   - Vejledning i identificering af patienter via DAK-E
     - Medicin pop-up
   - DSAM vejledning (Evt. præsentation af app)
   - Tryghedskassen (der findes allerede undervisningsfilm om subcutan nål, medicin og væske.) Se: http://www.auh.dk/om+auh/afdelinger/onkologisk+afdeling+d/information+til+patienter/behandlingsafsnit/det+palliative+team/for+fagfolk/subkutan+n%c3%a5l
     - kommer desuden snart som E-læringsprogram.
   - Det Palliative teams rolle
   - Terminal erklæringer
   - Medicinbevilling
   - Kontakt til hjemmeplejen
     - Indhold henvisning
   - Regionale og lokale tilbud
   - Patientforeninger og øvrige tilbud
     - Kræftens Bekæmpelse
     - Børn og unge og sorg
     - Ældresagen
     - Hjerteforeningen
     - Chatføra
<table>
<thead>
<tr>
<th>Påsigt til</th>
<th>Materialer</th>
<th>Oplægsholder og aktivitet</th>
<th>Ansigt tid</th>
<th>Tema</th>
<th>Hviad er palliation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tema</td>
<td>Hvad er palliation?</td>
<td>Intro og velkomst til et spændende og aktivt efteruddannelsesmøde om palliation i Almen praksis, der skal skabe refleksion og tank om mulige ændringer i praksis.</td>
<td>40 min</td>
<td></td>
<td>Budskabet</td>
</tr>
<tr>
<td>Indhold og form</td>
<td>Budskabet</td>
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<td>Budskabet</td>
<td></td>
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<tr>
<td>Materialer</td>
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<tr>
<td>Tema</td>
<td>Hvad efterstår patienterne?</td>
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<tr>
<td>Indhold og form</td>
<td>Genkendelse af patienter med komplext forløb (Cancerpatient, med komplikationer, medicinsk praksis, fortid)</td>
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<tr>
<td>Materialer</td>
<td>- manglende viden om palliation (Cancerpatient, medicinsk praksis, fortid) - manglende viden om symptombehandling (Cancerpatient, medicinsk praksis, fortid) - manglende viden om palliative process (Cancerpatient, medicinsk praksis, fortid) - manglende viden om palliative process (Cancerpatient, medicinsk praksis, fortid)</td>
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<tr>
<td>Oplægsholder</td>
<td>Oplægsholder fra egne praksisforsøg.</td>
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<tr>
<td>Anslået tid</td>
<td>45 min</td>
<td></td>
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<tr>
<td>Budskabet</td>
<td>At give deltagerne viden om patienternes ønsker, den nyeste viden om gode palliative forløb og barrierer for gode palliative forløb</td>
<td></td>
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</tr>
</tbody>
</table>
Vil de have kontakt med patienten
oversætt kræften i først
og omgang
Hvilken
adfærdsændring
tiltræber vi
Opsamling på
 temaet
Lægerne skal mærke efter hvor i egen adfærd
og struktur, der er barrierer i forhold til at få
standardiseret palliative indsats.

Fælles opsamling af drøftelse.
Konsulent stiller spørgsmål til salen, evt. et udvalgt bord.

Evt. flipboard til løbende notering af barrierer,
eller håndtak eller indskrivelser.

Oversætt spørgsmål til salen, vkt. udviglet bord.

Lægerne skal mærke efter hvor i egen adfærd
og struktur, der er barrierer i forhold til at få
standardiseret palliative indsats.

Konsulent stiller spørgsmål til salen, et udvalgt bord.

Lægerne skal mærke efter hvor i egen adfærd
og struktur, der er barrierer i forhold til at få
standardiseret palliative indsats.

- oversætt spørgsmål til salen, lav afspændende forhindringer
- oversætt spørgsmål til salen, lav afspændende forhindringer
- oversætt spørgsmål til salen, lav afspændende forhindringer

Pause med mad

18:10-18:45
Tema: Praktiske tag med hjem - ting

Indhold og form:

Materialer

Oplægsholder

Anslået tid: 60 min

Anslaget tid

Oplægsholder

Materieler

Indhold af form

3. Tema

Hvilken

Hvad ønsker vi?

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Hvorfor er det?

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Hvad ønsker vi?

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Hvad ønsker vi?

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<table>
<thead>
<tr>
<th>Tema</th>
<th>Evaluering</th>
<th>Indhold og form</th>
<th>Materialer</th>
<th>Oplægsholder</th>
<th>Anslået tid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Budskabet</td>
<td>Vi vil gerne lave god undervisning, hvad synes I</td>
<td>Læring til næste efteruddannelse</td>
<td>budskabertilbud</td>
<td>budskabertilbud</td>
<td>15 min</td>
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<td>19.45-20.00</td>
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<td>Opvægning af form og afrunding</td>
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<td>Spørgeskema til efteruddannelse og udvalges til et mini interview, sker ved enkeltforhøret</td>
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<td></td>
<td>Evaluering og Opvægning af form og afrunding</td>
</tr>
</tbody>
</table>
Corrections

Corrections of references in chapter 3, part 3.3. on page 40 for the following section:

The facilitators which could amplify the effect of the intervention were identified to be: case-based teaching, guidance rather than orders, educational meetings in small groups, engaging with peers, active participation, sharing experiences among peers with end-of-life care, involving opinion leaders, encounters with specialist [1-4].

References:


