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BARCERS TO PALLIATIVE CARE IN PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE IN HOME CARE: A QUALITATIVE STUDY OF THE PERSPECTIVE OF PROFESSIONAL CAREGIVERS

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Contributions

Study design: CAM, KL, HT & MK; Data collection: CAM; Analysis and interpretation: CAM, KL, HT & MK; Manuscript preparation: CAM, KL, HT & MK.

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The authors declare that there are no conflicts of interest.
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TITLE

Barriers to palliative care in people with chronic obstructive pulmonary disease in home care: A qualitative study of the perspective of professional caregivers

ABSTRACT

Aims and objectives: To examine the experiences with palliative care in people with chronic obstructive pulmonary disease among professional caregivers in a Danish home care setting.

Background: Many patients with advanced chronic obstructive pulmonary disease (COPD) depend on professional caregivers in the primary sector to provide assistance and care. However, COPD patients receive no or only very little palliative care compared to patients with cancer although they may have many burdensome symptoms.

Design: Qualitative explorative study.

Methods: In 2013-2014, ten professional caregivers from three districts in a Danish municipality were followed during home visits to patients with chronic obstructive pulmonary disease and individual interviews about palliative care were subsequently conducted. In 2014, 66 professional caregivers, representing eleven home care districts,
participated in ten group discussions about palliative care needs in this group of patients. Data was analysed using qualitative descriptive analysis.

**Results:** The study revealed a non-awareness of palliative care for patients with chronic obstructive pulmonary disease among the professional caregivers who expressed vague understanding of palliative care and lack of knowledge about the disease. Organisational barriers, such as lack of time and continuity in patient care and lack of opportunity to discuss palliative care and lack of peer learning were experienced as challenging in the provision of palliative care. Non-awareness and organisational barriers led to difficulties in identifying PC needs and reluctance to initiate conversations about PC.

**Conclusion:** The findings indicate a need for education, training and reflection among professional caregivers in home care. Also, organisational changes may be needed to reduce the barriers to palliative care.

**Relevance to clinical practice:** The findings uncovered barriers to PC that must be addressed. Targeted educational programmes and organisational changes may increase the ability to identify palliative care needs and initiate and evaluate palliative interventions.

**Keywords:** Chronic Obstructive Pulmonary Disease; Community Nursing; Palliative Care; Qualitative Study; Interviews; Community Care
What does this paper contribute to the wider global clinical community?

- Professional caregivers (registered nurses, social and healthcare assistants and helpers) in home care settings experienced vague understandings of palliative care (PC), lack of knowledge about chronic obstructive pulmonary disease (COPD), a challenging structure in home care and lack of time and continuity in the care for home-dwelling patients with COPD.
- Professional caregivers experienced powerlessness and a lack of confidence when providing care for home-dwelling patients with severe COPD symptoms.
- A need for further education and training were revealed to identify PC needs and initiate PC interventions for patients with COPD among frontline professional caregivers in home care settings.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a slowly progressing disease causing damage to the airways and impairing flow of air to and from the lungs (Decramer & Vestbo 2016). COPD is a leading cause of morbidity and mortality (Devereux 2006). It is estimated that COPD will become the fourth leading global cause of death in 2030 (Decramer & Vestbo 2016). From previous studies it is known that the trajectory of COPD is unpredictable (Lopez-Campos et al. 2013; Kessler et al. 2011) and patients are often housebound due to their COPD and may experience depression or low quality of life (Garrido et al. 2006; Jones et al. 2011), as well as other debilitating symptoms. Thus, home-dwelling patients with COPD may experience palliative care (PC) needs in everyday life and professional caregivers in home care has been suggested to be well placed to address the PC needs (Pinnock & Sohanpal 2016). However, there is limited research on PC administered in the home to persons suffering from COPD, particularly within the Danish context.
BACKGROUND

The growing number of people with advanced COPD leads to more specialised care tasks in the primary care sector (Disler & Jones 2010). Traditionally, the target group for PC has been patients suffering from terminal cancer (Weil et al. 2015). However, the World Health Organization (WHO) states that ‘palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness’ (World Health Organization 2002). This definition emphasises that PC is not associated with a specific disease and suggests that early PC interventions might be called for. It is thus the diagnosis of ‘a life-threatening disease’ that determines the need for PC. Patients with COPD often live with the condition for many years and it is difficult to predict the individual disease trajectory (Patel et al. 2012). COPD is defined as a life-threatening disease and patients have several symptoms such as dyspnoea, fatigue, cough, anxiety, and/or social isolation (Giacomini et al. 2012). Even though COPD may not in the early phase be life-threatening, patients may experience life limiting symptoms and concerns. Thus, the care of professional caregivers should reflect knowledge that patients with COPD may experience PC needs in all stages of the disease (Lanken et al. 2008). Research has shown that patients with COPD are ‘silent’ and do not complain and speak up about their condition (Habraken et al. 2008). Previous research indicates that patients with COPD receive less PC than patients with comparable symptoms and prognoses (Gore et al. 2000; Elkington et al. 2005; Carlucci et al. 2012). Moreover, the quality of PC interventions for people with COPD seem to be poor compared with the care received by patients with cancer (Elkington et al. 2005; Curtis 2008; Gardiner et al. 2010).
Little attention has been paid to how professional caregivers will be able to identify the PC needs in people with COPD. It has been suggested to work with trigger points or milestones for introducing PC (Pinnock et al. 2011). Milestones are specific points in the disease process where it seems relevant to assess the need for PC. Studies highlight diagnosis, retirement, exacerbation, losing an informal caregiver, and starting oxygen therapy as relevant milestones (Pinnock et al. 2011; Landers et al. 2015). Several international studies have revealed that doctors and nurses experience barriers in providing PC interventions for people with COPD. These barriers include vague definitions of PC (Disler & Jones 2010; Pinnock et al. 2011; Philip et al. 2012), confusion about timing of PC (Pastrana et al. 2008), fear of destroying patients’ hope (Knauf et al. 2005; Spence et al. 2009; Pinnock et al. 2011; Crawford et al. 2013) and limited time to discuss PC with patients (Gott et al. 2009; Disler & Jones 2010; Stajduhar et al. 2011; Philip et al. 2012). However, little is known about the possible barriers to PC experienced by Danish RNs, social and healthcare assistants and helpers in home care settings.

In Denmark, the context for this study, the political focus on general PC was increased in 2011 and reflected in national recommendations from the Danish National Board of Health (National Board of Health [Sundhedsstyrelsen] 2011). The National Board of Health recommended an increased focus on PC in basic healthcare education programmes no later than 2013. In Denmark, the care for patients with COPD is shared between hospitals (specialist care), general practitioners (GPs) and the municipality (primary care services) (Lange 2012). Home-dwelling patients with COPD can receive help from public primary care services (provided by registered nurses (RNs), social and healthcare assistants and helpers) for tasks like e.g. personal hygiene, household chores and/or administration of medicine.
Patients receiving home care in their own homes have continuous contact with professional caregivers and hence the opportunity to discuss their disease, symptoms, concerns and questions. In the organisation of Danish home care services RNs and social and healthcare assistants and helpers therefore have a crucial role in caring for patients with COPD. However, little is known about the Danish professional caregivers’ understanding of PC in regard to patients with COPD in home care.

In the current study we investigated the experiences of PC among professional caregivers in home care. This study addresses the following questions: a) how do professional caregivers understand PC for patients with COPD in home care settings? b) what are the major barriers in providing PC? and c) what could increase the ability to meet the PC needs of patients with COPD according to professional caregivers? Throughout this study professional caregivers refer to RNs and social and healthcare assistants and helpers.

**METHODS**

**Design**

To study professional caregivers’ experiences, we used qualitative methods consisting of individual interviews and group discussions. We chose to conduct individual interviews with professional caregivers because this method offered an opportunity to gain deep insight into the professional caregivers’ perspective. Subsequent group discussions were conducted to elaborate on the findings from the individual interviews and in group discussions participants could influence each other and respond to the comments of others. Data from
individual interviews and group discussions were interpreted using qualitative descriptive analysis as described by Sandelowski (Sandelowski 1995; Sandelowski 2010). This article is one of two reports describing the results of the first phase of an action research study about PC in home care settings among patients with COPD.

**Settings and participants**

Data collection was performed in a large Danish municipality from December 2013 to September 2014. Home care services in this municipality was organised in eleven home care districts. Ten professional caregivers from three districts (urban and rural districts, day and night shifts) were followed during visits in the patients’ homes and were later interviewed individually (II). The reason for inviting only three districts to participate in the individual interview phase had to do with the capacity in the municipality and the three districts were considered representative for the municipality. Professional caregivers in the three districts were asked to identify patients with COPD and ask the patients for permission to invite the researcher into their homes. The patients were identified and recruited using purposive sampling and the inclusion criteria were: Diagnosed with COPD, receiving regular help from professional caregivers, speaking and understanding Danish and agreeing to participate. The patients were interviewed individually after the observational visits. These data are presented elsewhere (Authors, in review). There were no criteria regarding disease severity or special tasks to be performed by the home care services in the patients’ home because PC needs were considered possible in all stages of COPD. The ten professional caregivers who participated in the observed visits in patients homes were individually interviewed. To further elaborate on the findings from the individual interviews, professional caregivers
from all eleven districts in the municipality participated in ten group discussions (GD) (3-8 participants in each group) (Table 1). Each home care district was given the opportunity to enrol a maximum of ten professional caregivers in the group discussions and a total of 66 participants were enrolled. Inclusion criteria were RNs, social and healthcare assistants and helpers in home care settings, delivering care to patients with COPD, and the ability to understand and speak Danish. The objective was to share experiences and opinions on PC for patients with COPD.

**Data collection**

To prepare for conducting the individual interviews with the professional caregivers the first author followed ten caregivers during thirteen visits in the homes of patients with COPD to obtain a background understanding of professional caregiver routines and to get to know the patients and the professional caregivers. The researcher primarily had the role of an observer. During the visits the observer engaged in informal conversations with both professional caregivers and patients. The field notes from the observations were used to adjust the interview guides used.

**Individual interviews**

Ten professional caregivers (one RN, two social and healthcare assistants and seven social and healthcare helpers) were interviewed individually within one week after the visit in the patient’s home to gain insight into their professional experiences of working with PC in patients with COPD. Each professional caregiver was interviewed once. The interview took
place at the professional caregiver’s workplace and was audio-recorded. Based on the research question, a systematic literature search and data from the observational visits, a thematic interview guide was developed. The interview guide included questions like: What do you think of when you hear the word PC?, What, if any, challenges do you meet when taking care of patients with COPD? and What do you need to be able to increase your competencies in PC for patients with COPD? Preliminary analyses of data from the individual interviews were used to develop the questions for the subsequent group discussions.

**Group discussions**

Ten group discussions among a total of 66 professional caregivers (3-8 in each group) from all 11 districts in the municipality were conducted in August and September 2014. The group discussion sessions took place in three different districts and lasted approximately 1.5 hours; discussions were audio-recorded. Seven group discussions were completed with mixed professional groups and three discussion groups were completed in mono-professional groups; one group of social and healthcare helpers, one group of social and healthcare assistants and one group of RNs. Five major questions were discussed during the discussion sessions encouraging professional caregivers to elaborate on their experiences with PC in relation to patients with COPD through peer interactions. The major questions were: What is PC and who needs PC? What are the challenges in working with patients with COPD? How do you identify PC needs? Do you initiate discussions about the future? and Are you able to respond to patient’s PC needs? The first author served as a facilitator during the sessions including keeping track of time, questions and creating a dynamic and trusting environment. The professional caregivers were invited to share experiences and opinions and discuss different perspectives on palliative care of COPD patients.

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Data analysis and interpretation

The analysis consisted of two phases: "Getting a sense of the whole" and "Developing a system". First, all recordings were carefully listened to for obtaining a deep understanding of the content. Secondly, a systematic approach to the data was used, designating with the simplest word possible the topical area being discussed in the data (see table 2 for an illustration of the process).

According to Sandelowski (1995), the idea is to have a topic list that ‘is as parsimonious as possible, but one that will capture all of the topics present in the data’ (Sandelowski, 1995, p. 374). Codes were generated from the data during the course of the analysis and revealed 115 codes. The coding was conducted by the first author and the identified codes were discussed in the research team. These codes were synthesised and categorised into three major themes (Table 2).

Ethical considerations

Prior to commencing the study, ethical approval was obtained from local administrators in home care and the Danish Protection Agency (j.nr. 2013-41-1999). All participants were informed about the study, voluntary participation, confidentiality and anonymity. Participants in the individual interviews provided verbal and written consent before being interviewed. In the group discussions, participants provided verbal consent.
FINDINGS

The analysis revealed three major themes with related sub-themes that captured the professional caregivers’ understanding of PC needs among patients with COPD and the perceived barriers for a PC approach. The major themes were: 1) Non-awareness of PC needs in patients with COPD, 2) Organisational barriers to a PC approach and 3) Consequences of non-awareness and organisational barriers (figure 1).

Non-awareness of PC needs in patients with COPD

The theme ‘Non-awareness of PC needs in patients with COPD’ included two sub-themes, which are described below.

Vague understanding of PC

The professional caregivers were confused about what PC entailed. The interviews revealed that PC is not a concept that is commonly used in home care settings. RNs, social and healthcare assistants and helpers did not know how to explain the concept of PC. Most professional caregivers were able to translate the word palliation to relief, as in relieving symptoms, but a majority of professional caregivers were not able to elaborate on their understanding of PC in patients with COPD. As reported by a social and healthcare helper:

“I do not know what PC interventions for patients with COPD could include”
(IIG)

Professional caregivers typically thought that PC was offered to patients with cancer and that initiatives primarily concerned pain management. PC was seen as an intervention for
terminally ill patients. It was a major challenge for PC that professional caregivers did not think of patients with COPD as being a target group for PC. Thus, there was a non-awareness of PC needs in this patient group. As described by a RN:

“I do not think of palliation when entering the homes of patients with COPD. That’s not what my work is based on” (IID)

Lack of knowledge about COPD

The professional caregivers reported lacking knowledge about PC, COPD and tools to manage COPD symptoms such as dyspnoea and anxiety. A few professional caregivers expressed a need for instructions or checklists to support them in identifying needs. Professional caregivers felt poorly prepared to care for patients with COPD, especially in acute situations and when talking about the future, death and dying. Professional caregivers reflected on being employed in home care one needs to be a generalist and to know about a lot of potential diseases and situations in patients’ everyday life. Despite years of experience, some of the professional caregivers still felt ill prepared to perform PC in patients with COPD. They reported to lack general knowledge about COPD such as anatomy, pathophysiology and medical treatment. As described by two of the professional caregivers:

“I need to know more to be able to talk about the future” (IIA), “I know nothing about the disease (...) I experience a lot of ‘learning by doing’... we need more education” (GD4)
Professional caregivers reported to use breathing techniques in handling patient’s dyspnoea, but only very few had been formally trained and educated in this. Many of the professional caregivers reported that they had never thought of breathing techniques as a PC intervention.

Professional caregivers reported that being around patients with COPD sometimes made them feel anxious: “What am I getting into?” (IIC), and they explained to continue feeling anxious after completing the home care visit, thinking of the situation as a ‘scary’ experience. Feelings of insecurity or inadequacy among professional caregivers were illustrated by the following quotes:

“Sometimes I feel insecure. Could I have done more before just calling 9-1-1. Do I know enough?” (GD6); “I do feel stupid when I can’t come up with something to do in the acute situation” (GD1); and “I get this feeling of inadequacy, but I am not able to know everything” (IID).

Furthermore, the professional caregivers expressed a clear interest in knowing more about the patient perspective. They wished for patients with COPD to tell about everyday life with COPD and enlighten them on opportunities to relieve their symptoms and concerns.

**Organisational barriers to a PC approach**

This theme also included two sub-themes, which are described below.

**A challenging structure in home care**

The current study revealed several challenges concerning the organisation of PC in home care for patients with COPD. The organisation of care in the eleven districts differed slightly,
but the overall structure was that social and healthcare assistants and helpers worked together in teams with a district RN as a clinical supervisor. The districts were in some cases further divided into units to avoid too much travel time between the workplace and the patients’ homes. RNs were in most cases placed in offices detached from the other home care staff. According to the professional caregivers, this structure was not conducive for continuous multidisciplinary discussions about patients and their potential PC needs. Some professional caregivers experienced that the physical separation of staff complicated the possibility of knowing and learning from each other. Professional caregivers reported that working in home care was an independent job. In contrast to professional caregivers in nursing homes or hospitals, they did not have colleagues nearby to consult. The different professional caregiver groups often only met a few times a week for brief scheduled meetings. The professional caregivers generally expressed a need for more interdisciplinary discussions and they stressed being dependent upon exchanging knowledge. The professional caregivers experienced that the structural organization of home care made it difficult to use the various professional skills among colleagues, although they stressed being dependent upon exchanging knowledge:

“Professional groups experience different things (...) Professional caregivers are educated differently. We [different staff groups] cannot do without each other” (GDS5)

The social and healthcare helpers reported to discuss patient-related problems with other social and healthcare helpers or assistants if they felt the need for help and if unsuccessful they contacted the district RN. Professional caregivers working in the evening or nightshifts felt even more alone in their job. They did not attend weekly meetings and often
experienced to lack information; this made them highly dependent on the documentation skills of their colleagues.

**Lack of time and continuity**

Identifying PC needs and talking to patients about their possible concerns require time and continuity. The professional caregivers experienced lack of time as a major barrier. The majority of professional caregivers reported that a very tight time schedule for their visits to the patients' homes was an obstacle to assessment of PC needs through conversation:

“If you are going into a serious conversation with the patient about the future or death you should be able to guarantee to stay and finish the conversation. Otherwise you shouldn’t enter [the conversation]” (GD2)

The professional caregivers reported that their assignments had a strong focus on practical tasks in the home, whereas talking to patients about feelings or concerns and being able to spend time with the patients were not allotted time. Reflecting on the question of PC, the professional caregivers felt that PC was an additional or secondary task. They expressed that they needed to ‘steal’ time for non-practical tasks. One social and healthcare helper said:

“Patients have been assigned practical help, but we need to steal time for PC (...) We have to steal time for deep conversations – to prioritise how we spend the allocated amount of time” (IIF).

One professional caregiver was very keen on changing the habits of performing services in secret. She maintained that by ‘stealing time’ from other tasks, it would never be visible to the managers what patients really needed and how much time professional caregivers needed for performing PC.
Organisational challenges also concerned the work schedules for the professional caregivers. Even though the managers tried to plan the work in a way that considered the individual patient, the professional caregivers experienced a lack of continuity, which challenged their ability to identify changes in the patients. The patients with COPD met frequently changing staff and the professional caregivers reported that this unpredictability caused insecurity and frustration among patients.

**Consequences of non-awareness and organisational barriers**

Vague understandings of PC, lack of knowledge about COPD, a challenging organisation of home care as well as lack of time and continuity caused several difficulties. The theme ‘consequences of non-awareness and organisational barriers’ included two sub-themes, which are described below.

**Difficulties in identifying PC needs of patients with COPD**

As presented in the theme about non-awareness of PC needs in patients with COPD, the professional caregivers experienced vague understanding of PC and a lack of knowledge about COPD. Identifying PC needs based on knowledge of the disease and possible palliative interventions was not a routine and the professional caregivers did not address the patients’ PC needs systematically. Not knowing exactly what PC meant and which specific PC needs patients could experience when having COPD, impeded their ability to look for something specific. As reported by a social and healthcare helper:

“How am I supposed to identify PC needs when I am confused about the definition of palliation?” (IIA)
This lack of knowledge about PC was further complicated by organisational barriers. A lack of time and continuity resulted in difficulties in identifying PC needs, as professional caregivers reported that spending time with patients was necessary to get to know the patient well. Furthermore, lack of continuity in the professional caregivers’ visits challenged the ability to detect changes in patient status, thereby giving poor conditions for identifying e.g. PC needs. Lack of continuity also resulted in difficulties in consulting colleagues and learning from peers. Thus, the structure was a barrier for mutual learning across disciplines and staff.

Reluctance to initiate difficult conversations with patients

Lack of knowledge and experience with PC in relation to COPD sometimes made caregivers feel inadequate. This feeling of inadequacy served as a personal barrier to initiate difficult conversations with the patients. Professional caregivers reported to be reluctant to initiate difficult conversations unless they knew the patient very well. A good relation was seen as fundamental for creating the proper surroundings and framework for conversations about PC. One of the professional caregivers described this in the following way: “I must be absolutely certain to have earned the patients’ confidence before I initiate difficult conversations” (IIA). Another professional explained: “Knowledge of the patient is necessary. I do not push the patient into talking (...) You have to catch the ball when it is there” (GD3).

To catch the ball was used as a metaphor in several interviews meaning to seize the opportunity. The professional caregivers reported implicit and explicit signs of the need for conversations. The implicit signs were e.g. when the professional caregivers observed that the patient seemed scared or worried, but the patient did not verbalise this. The explicit signs were e.g. when patients expressed to be afraid or worried about something related to
their disease or the future. Professional caregivers reported that both the patient and the professional caregivers could initiate conversations about the future, death and dying, but the professional caregivers shared a common perception that it would be best if the patient opened these conversations themselves. One professional expressed it this way:

“It's easier if they [the patients] take the initiative. I think talking about the future and possible concerns exceeds some limits. It can make patients sad” (GD7).

A fear of not having the required skills often prevented professional caregivers from initiating the conversations:

“I think we [the health professional caregivers] are the ones who are often afraid, I know I am, or maybe not afraid, but I feel insecure” (GD8).

Some of the professional caregivers expressed to be afraid of destroying patients’ hopes for the future or even hurt the patient by initiating conversations about the future, death and dying. The professional caregivers told that introducing PC could make the patients’ “alarm bells go off” as PC was associated with efforts in the last phase of life, meaning terminal care. The awareness of maintaining hope was described as:

“You need hope until you close your eyes [dies]. We must be careful not to take hope away from patients. If you have first crushed a person’s hope, only hopelessness remains” (IIE)

Not all professional caregivers shared the view that they would destroy patients’ hopes by starting conversations about the future, death and dying. A few expressed to talk to patients about their concerns. However, this was often based on an acute episode and rarely
happened without being triggered by particular event. Fear of initiating conversations could perhaps prevent patients from achieving relief. However, professional caregivers agreed that the risk of destroying patients' hope depended on the communication skills of each professional caregiver:

“Perhaps we can even provide hope? (...) We can present possibilities” (GD2)

In summary, a common view among the professional caregivers was that they did not think of PC as a part of caring for patients with COPD. To be able to perform PC and initiate palliative conversations for this group of patients they experienced a need for more knowledge about PC and COPD, and an organisational structure of home care focused on continuity and enough time in patient’s home. Moreover, professional caregivers expressed a need for discussing and learning from peers about PC and COPD.

DISCUSSION

Our findings revealed a non-awareness of PC needs and COPD and therefore also PC in patients with COPD in home care. These findings are in line with the findings of Disler and Jones (2010), who argued that lack of understanding of the need for PC in patients with COPD led to patients being ‘invisible’ to community services.

The professional caregivers had a vague understanding of PC, which is consistent with (Pastrana et al. 2008), who found a lack of a consistent meaning of the term. A lack of understanding of PC influences how health care is practiced, which was evident in our study. We found that the vague definition of PC resulted in insecurity regarding identification of PC needs, uncertainty about the professional caregivers' competencies in relation to PC and fear or reluctance to initiate conversations about PC. In a systematic review (Coventry et al.

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2005), it was suggested that the biggest barrier for receiving PC when having a non-malignant life-threatening disease was related to the professional caregivers’ reluctance and/or inability to define patients’ palliative status and predict the course of the disease. We therefore suggest that professional caregivers need continuing education and training, including discussions about the definition of PC in a COPD context to be able to have a PC approach and focus in the care of patients with COPD.

Our finding about reluctance to initiate conversations about PC in home care confirms previous studies concluding that some healthcare professionals are frequently reluctant to raise discussions about PC spontaneously even though they feel these discussions would be useful for the patients (Pinnock et al. 2011). In the current study, professional caregivers experienced limited knowledge and low confidence in their own skills, which may be a possible explanation of the reluctance or inability to talk to patients about PC needs and/or interventions. In a previous study (Authors, accepted for publication), patients with COPD expressed wishes to discuss their disease, symptom management, the future and death with professional caregivers, but rarely took the first step to have these conversations. Pinnock et al. (2011) suggest that discussions about PC should occur as a matter of routine and not wait until the patients asked for information. In the current study some professional caregivers asked for instructions or checklists to help them identify PC needs. Systematic use of tools may legalise conversations about PC by assisting professional caregivers to discuss difficult and sensitive aspects of care and improve the dialogue with the patient (McIlfatrick S & Hasson F 2014).
In line with previous research, our study found that all professional staff groups had considerations about the risk of destroying the patients’ hope for the future by talking about PC needs and interventions (Giacomini et al. 2012). The fear of destroying the hope of patients with COPD reflects an understanding of hope as essential for human existence. The understanding that hope is essential for human existence, and especially for people facing life-threatening illness, has been described previously (Penz 2008; Giacomini et al. 2012; Olsman et al. 2014). Very few studies have been conducted focusing on hope and PC in relation to COPD sufferers. A Danish qualitative study concluded that patients with COPD do not consider conversations with professional caregivers about disease, the future and death to be a threat to their hopes for the future (Authors, accepted for publication). Not all health care professionals have the skills to pursue PC in patients with COPD and some prefer to let the patients initiate end-of-life discussions (Giacomini et al. 2012). The current study revealed a need for development of competencies among professional caregivers concerning knowledge about COPD, PC, medical treatment and techniques to manage COPD symptoms and how to share these concerns with the patients.

The current study revealed organisational challenges related to organisation, work schedules, continuity and time to perform PC. In the home care districts studied, PC was considered a job for RNs. This implied challenges as patients with COPD often do not receive help from primary care RNs until very late in their disease trajectory. Therefore, the staff members responsible for caring for patients with COPD are often the ones with the shortest education. The patients are dependent on the social and healthcare helpers or assistants’ ability to identify the need for PC and for contacting the RN to receive help or advice,
conduct an assessment of PC needs and initiate PC interventions. To be able to identify changes in patient status, the professional caregiver needs to know the patient well and visit regularly in the patients’ home. The current study revealed that the organisation of care services challenged the ability to spend the time needed in patients’ homes to identify PC needs and that staff was often shifting. Lack of time and structural challenges were also addressed in a previous study stating that health professionals are faced with extreme time constraints in their clinical work (van Riet Paap et al. 2014), and that the infrastructure of a service can be a barrier to improving PC.

Participating in the current study seemed to have initiated an interesting, though unintended process among professional caregivers. In the research team we witnessed how professional caregivers started to develop an understanding of PC as a relevant intervention for patients with COPD. From the individual interviews it became clear that professional caregivers were unaware of PC needs and interventions in relation to taking care of patients with COPD. From the group discussions we found that most professional caregivers started off with a non-awareness of PC needs for patients with COPD. Being introduced to the aims of the research study and participating in discussions with colleagues about PC for patients with COPD, initiated a perception of PC as being both important and relevant. This may be interpreted as an emerging movement from non-awareness towards an initial awareness of PC needs of patients with COPD among professional caregivers. The questions from the interview guide caused professional caregivers to reflect on the challenges they faced in home care as well as on possible solutions to meet these challenges. This observation of an initial awareness of PC after participating in group discussions may indicate that reflective group discussions can be a way to develop common perceptions of complex concepts in
home care as well as to discover the need for knowledge and skills to be able to perform PC in patients with COPD.

**Strengths and limitations**

This study presents knowledge regarding professional caregivers’ experiences and challenges regarding provision of PC to patients with COPD in home care. The findings are specific to PC for patients with COPD but may be transferable to other groups not traditionally associated with PC, e.g. elderly and debilitated home-dwelling persons. The study was performed in only one, though large, Danish municipality which may limit the extent of our findings. We are aware that there are variated levels of focus and in-service education of caregivers in relation to PC in different institutions, municipalities and regions in Denmark. However, our knowledge of Danish municipalities tells us that the study municipality is in no way extraordinary. The study included a large group of home care staff and we have used viable methods to investigate the perspectives of professional caregivers, e.g. individual interviews and group discussions. These methods were combined to provide in-depth knowledge. In the group discussions we aimed for approximately six participants in each group. However, one group consisted of only three participants, as this was a mono-professional discussion group of social and healthcare helpers and we experienced cancellations on the day of the group discussion. The fact that the empirical data from three specific professional groups has been analysed as one group may be considered a study limitation. We are aware that the three professional groups have various qualifications and competence levels and conducting a systematic analysis on each professional group might have produced more specific knowledge of the perspectives of each professional group.

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However, during both individual interviews and group discussions it became clear that all professional caregiver groups were challenged in identifying PC needs and initiating PC interventions. Having the three professional caregiver groups attending joint discussions may have represented a risk of a predominance of RNs opinions compared to those of lower levels of education. However, listening to the digital recordings we did not find reason to suspect that this was the case. We have included quotes from the data material to provide credibility and to support the findings.

CONCLUSIONS

The study uncovered non-awareness of PC needs in patients with COPD and a lack of knowledge about PC for this group among professional caregivers. It also found that organisational barriers impeded PC. Lack of knowledge and organisational barriers led to several consequences concerning the ability to initiate difficult conversations and the ability to identify PC needs. The findings of this study suggest a need for education, training and reflection among professional caregivers in the home care sector. Also, organisational changes may be needed in home care to reduce the barriers to PC interventions for patients with COPD.

Relevance to clinical practice

The findings of this study contribute to understand the needs and challenges that must be addressed in targeted interventions aimed at increasing the professional caregivers’ ability to identify PC needs and initiate and evaluate PC interventions among patients with COPD.
home care settings. An educational programme designed for frontline staff in home care settings could be a possible solution to address the identified barriers to PC for patients with COPD.

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<table>
<thead>
<tr>
<th>Data source:</th>
<th>Abbreviation:</th>
<th>Total number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual interviews</td>
<td>II</td>
<td>10 (ten individuals) (coded as IIA-J)</td>
</tr>
<tr>
<td>Group discussions</td>
<td>GD</td>
<td>10 GDs (coded as GD1-10) (including 66 individuals)</td>
</tr>
</tbody>
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Table 1: Data sources
<table>
<thead>
<tr>
<th>Quotes</th>
<th>Sub-themes</th>
<th>Major themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Palliative care? I don’t know... I don’t know what that means... the palliative care team [specialized team]? But not for COPD. It is for patients with cancer or treatment of pain” (IIB)</td>
<td>Vague understanding of PC</td>
<td>Non-awareness of PC needs in patients with COPD</td>
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<tr>
<td>“When you hear about palliative care, it is often in the last phase of life (...) You associate it [palliation] with something else [than COPD]. It is synonymous with terminal care... and the palliative care team [specialized team]” (GD4)</td>
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<td>“I generally experience a lack of knowledge about COPD (...) It is difficult to teach the patient when you don’t know enough about COPD yourself” (IIH)</td>
<td>Lack of knowledge about COPD</td>
<td></td>
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<tr>
<td>“I feel totally unequipped for the job. I know nothing about the disease (...) We need knowledge about COPD – everyday life with COPD – how can everyday life get better?” (GD10)</td>
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<tr>
<td>“Collegial discussions are important. I don’t know where to get help (...) First and foremost we have each other [the Nursing team] and physiotherapists and occupational therapists (...) We need supervision among colleagues (...) Working in patients’ homes is an independent job – You [professional caregiver] do not have colleagues nearby to talk to” (GD4)</td>
<td>A challenging structure in home care</td>
<td>Organisational barriers to a PC approach</td>
</tr>
<tr>
<td>“Professional groups experience different things (...) Professional caregivers are educated differently. We [different professional groups] cannot do without each other” (GDS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“I need to know the patient well – to spend time in the home – if I should be able to identify any changes” (IIG)</td>
<td>Lack of time and continuity</td>
<td></td>
</tr>
<tr>
<td>“It is difficult to prioritise as we are subject to tight time schedules” (GD5)</td>
<td></td>
<td></td>
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<tr>
<td>“How am I supposed to identify PC needs when I am confused about the definition of palliation?” (IIA)</td>
<td>Difficulties in identifying PC needs of patients with COPD</td>
<td>Consequences of non-awareness and organisational barriers</td>
</tr>
<tr>
<td>“I am not able to identify PC needs – I don’t know what to look for” (IIJ)</td>
<td></td>
<td></td>
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<tr>
<td>“We do not have a conscious palliative approach. Unconsciously we may provide PC. If we became more aware of PC it would increase the focus on PC needs“ (GD8)</td>
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<tr>
<td>“They [the patients] probably know where the disease is taking them (...) I think it exceeds some boundaries [to initiate conversations about PC]. It makes them [the patients] sad. It is better if the patients take the first step. It is more easy if they [the patients] initiate the conversations” (GD7)</td>
<td>Reluctance to initiate difficult conversations with patients</td>
<td></td>
</tr>
<tr>
<td>“It is difficult to take the initiative to talk about death. You need to be good at reading the patient’s signals. A good relationship is necessary. It is easier if the patients initiate the conversations. We do not want to hurt the patients (GD8)</td>
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Table 2: Illustration of the analysis process

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Figure 1: Schematic overview of the three themes

- **Non-awareness of PC needs in patients with COPD:**
  - Vague understanding of PC
  - Lack of knowledge about COPD

- **Organisational barriers to a PC approach:**
  - A challenging structure in home care
  - Lack of time and continuity

- **Consequences of non-awareness and organisational barriers:**
  - Difficulties in identifying PC needs of patients with COPD
  - Reluctance to initiate difficult conversations with patients