

Participation in healthcare – between power and powerlessness

**A qualitative longitudinal study of COPD patients'
and their family members' experiences during and after
hospitalization for a severe exacerbation in COPD**



PhD Thesis Ingrid Charlotte Andersen

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Odense University Hospital/Department of Clinical Research,
Faculty of Health Sciences, University of Southern Denmark**

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PhD Thesis

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A qualitative longitudinal study of COPD patients' and their family members' experiences during and after hospitalization for a severe exacerbation in COPD

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This thesis has been accepted for defence of the PhD by the Faculty of Health Sciences at the University of Southern Denmark and will be defended 15th of November 2017.

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Paper 2

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Paper 3

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1. Introduction

This thesis deals with a qualitative study of how patients with chronic obstructive pulmonary disease (COPD) and their family members experience the treatment and illness trajectory from being hospitalized for an acute exacerbation in COPD (AECOPD) and up to 18 months thereafter. The study explored aspects of COPD patients' and family members' experiences that related to their participation in healthcare, including issues concerning mutual relationships within the family and the interaction with healthcare professionals.

The basis for my studies in this field and the motivation for this project is my work in the promotion of quality of care and patient safety at a medical department in a Danish hospital. In recent years, increased patient and family participation in healthcare has dominated health policies and practices. Nevertheless, while greater patient and family participation is acknowledged as an important strategy to promote health outcomes, patient safety, quality in care, and reduce healthcare costs, it has become evident that, despite good intentions, individual patient and family participation can be difficult to achieve. For the further development and implementation of approaches and initiatives within healthcare, I therefore found it relevant to explore further, what it means to both patients and their families to be faced with an expectation to take an active approach to their care, both in the clinical setting and at home.

The central focus on COPD patients and families in this study is founded on my experiences over many years as a nurse working in a range of medical and acute care settings in hospitals. There, I have met COPD patients who have been admitted, and readmitted, with an AECOPD. They can be extremely vulnerable and their families can be burdened by worries. I realized how dependent they can be on appropriate help and support from healthcare professionals, both within and outside the hospital context. In order to better engage with these patients and families, there has become increased awareness on improving the continuity of care and preparing the patients to take an active part in their care on a daily basis. Strategies to promote greater participation in healthcare are an element in these efforts. In order to inform such strategies, the intention of this study is to generate in-depth knowledge, based on a coherent element of the COPD treatment and illness trajectory. This thesis intends to contribute to our understanding of what is at stake for COPD patients and family members in participation in healthcare before discharge from hospital and in their daily lives at home.

2. Background

Worldwide, chronic illnesses are the leading causes of death and disability, and constitute a considerable burden on the healthcare system (World Health Organization (WHO) 2017). In Denmark, around a third of the population has one or more chronic illnesses. In order to deal with the major tasks associated with treating chronic illness, the healthcare system is putting a growing focus on initiatives aimed at preventing, detecting, treating and rehabilitating people who are suffering from chronic illness. Importantly, the initiatives should contribute to enabling individuals to look after themselves as far as possible (Danish Health Authority 2017 a). Consequently, person-centred approaches with attention to the strengthening of individuals' capacity to self-manage their own condition are increasingly being considered promising to meet the challenges faced by the healthcare system (Coulter 2011). As mentioned in the Introduction, patients with COPD who go through a hospitalization for a severe AECOPD will be the focal point of this thesis. In the section that follows, an overview is presented about the development and course of COPD, the causes of COPD, the burden of COPD and selected elements from the Global Strategy for Diagnosis, Management and Prevention of COPD (Global Strategy for Diagnosis, Management and Prevention of COPD (GOLD 2017)).

2.1. The development and course of COPD

COPD is a common, preventable and treatable disease. It is characterized by persistent respiratory symptoms and airflow limitation that is due to airway and or/alveolar abnormalities (GOLD 2017). The most common respiratory symptoms include breathlessness, coughing and sputum production. These symptoms may be under-reported by patients and therefore COPD could be underdiagnosed (GOLD 2017). As COPD progresses, breathlessness increases on exertion, eventually leading to breathlessness at rest. Typically, COPD patients try to avoid exerting themselves and subsequently reduce their mobility. Occasionally, COPD patients experience episodes of acute exacerbation in COPD (AECOPD) and the number of these episodes can increase as the illness progresses. An AECOPD is triggered by infection, environmental pollutants or unknown factors, and is defined as an acute worsening of respiratory symptoms that result in additional therapy (GOLD 2017). Having an AECOPD can be seriously disabling and result in an urgent need for hospitalization and sometimes death. AECOPD has a negative impact on health status, rates of hospitalization and readmissions, and disease progression (GOLD 2017). Furthermore, COPD frequently coexists with concomitant comorbidities, e.g., cardiovascular disease, skeletal muscle dysfunction, metabolic syndrome, osteoporosis, anxiety and depression, or lung cancer, which may have a significant impact on prognosis (GOLD 2017).

2.2. The causes of COPD

The primary cause of COPD is active tobacco smoking. Other risk factors include exposure to second-hand smoke, indoor and outdoor pollution, and occupational dusts and fumes. Some cases of COPD are due to long-term asthma (WHO 2017). Besides exposures, genetic abnormalities, abnormal lung development and accelerated ageing predispose individuals to develop COPD (GOLD 2017). COPD is likely to increase in the coming years due to higher smoking prevalence and ageing populations in many countries (WHO 2017).

2.3. The burden of chronic obstructive pulmonary disease

Morbidity and mortality

COPD represents a major health problem all over the world. It leads to severe morbidity and mortality and represents a considerable economic and social burden worldwide. Around 64 million people in the world are estimated to have moderate to severe COPD. Since COPD is predicted to become the third leading cause of death by 2030, there is global focus on continuously optimizing its treatment and management (WHO 2017, GOLD 2017).

In Denmark, COPD-related morbidity and mortality are considerable. It is estimated that around 400,000 people in Denmark have COPD and that around 50,000 have COPD to a severe or very severe degree (The Danish Lung Association 2017). In Denmark, around 3,300 people, corresponding to 6% of all deaths, die each year of COPD as the primary cause of death. The mortality is higher than in any other European country; it increased in the 1990s, but there was a decrease and a stagnation in illness until 2010 (Flachs et al. 2015). COPD is one of the most frequent causes of hospitalization in departments of medicine in Denmark. More women than men are admitted due to COPD. The rate of admissions at hospital is currently slightly increasing, and the rate of readmissions within 30 days is about 19%. The mean length of stay at hospital is 5.4 days. Due to the extent of these consequences of COPD, there is a growing focus on cross-sectoral improvement of the illness and treatment journey of patients with COPD (Danish Health Authority 2017b).

The socioeconomic burden

Because of the high prevalence of the COPD and high rate of hospital admissions, the health economic consequences are considerable. COPD exacerbations account for the greatest proportion of the total COPD burden in the healthcare system, and the costs of care increase as the illness progresses (GOLD 2017). In the European Union, the total direct costs are estimated to be about 6% of the total healthcare budget, with COPD accounting for 56% of the cost of respiratory disease. In Denmark, the overall costs of COPD are estimated to 3.345 billion DKK per annum (Danish Health Authority 2017b).

The burden of living with COPD – according to patients' and their family members' experiences

Experiences of being afflicted by a severe AECOPD

The experience of being afflicted by a severe and life threatening AECOPD that requires hospitalization can be characterized by panic and fear of dying. In the acute phase of an AECOPD, having to deal with increased breathlessness, anxiety and fatigue, and going through intensive treatment and care, makes patients feel vulnerable and powerless (Kvangarsnes et al. 2013). Feelings of being dependent and traumatized by hospital routines exacerbate the difficulty of the situation. After discharge, experiences of increased levels of uncertainty about illness, prognosis, care and support can make recovery prolonged and demanding (Giacomini et al. 2012).

Experiences of living day-to-day with COPD

The sustained symptom burden and the psychosocial impact of the illness might contribute to experiences of having many daily obstacles when living with COPD in more severe degrees

(Disler et al. 2014). As the illness progresses, everyday life is often characterized by increased fluctuations in breathlessness and frequent shifts between experiences of good and bad days (Giacomini et al. 2012). The hereto-related unpredictability can make COPD hard to manage and fit into the daily life (Cooney et al. 2013). Consequently, experiences of vulnerability and sadness can dominate, and the need for help can increase. However, difficulties in managing social contacts with others often leave patients isolated from the help they need (Disler et al. 2012, Giacomini et al. 2012).

Experiences of family members involved in care

The impact of COPD on families can be considerable. Several studies reveal that severe COPD represents a significant burden to family carers (Cruz et al. 2017, Figueiredo et al. 2016, Nakken et al. 2015, Spence et al. 2008). Experiences of informal caring have been related to negative impacts on physical health, and on emotional, social, relational and financial dimensions – but it has also been more positively related to carers' experiences of being able to do something useful for their relative (Cruz et al. 2017). The unpredictability associated with severe COPD is found by family members to be stressful, because it makes daily decision making and activities difficult (Boyle 2009).

2.4. Global strategy for diagnosis, management and prevention of COPD

In order to raise awareness of the burden of COPD, the Global Initiative for Chronic Obstructive Lung Disease programme was initiated in 1998. A goal was to produce recommendations for management of COPD based on the best scientific information available. The recommendations are continuously revised – most recently in the report from 2017 (GOLD 2017). All over the world, the GOLD reports are used as guidelines to improve prevention and treatment of COPD.

Assessment and treatment of COPD

Assessment of the severity of COPD is important to make the diagnosis, to predict prognosis, and to guide treatment. The overall assessment is combined by an assessment of airflow limitation, symptoms, and exacerbation history (GOLD 2017). The severity of airflow limitation is identified by a spirometry and is classified in four grades, GOLD 1 to GOLD 4, where GOLD 4 is the most severe. Based on an assessment of patient-reported dyspnoea, and the history of exacerbation, patients are classified in four risk groups, A to D. Using these guidelines allows clinicians to individualize patient care that is sensitive to patients' symptoms at any given time and at any level of exacerbation risk (GOLD 2017). COPD is not curable, but treatment can relieve symptoms, improve quality of life and reduce the risk of death. Smoking cessation is the most effective and cost-effective available treatment for all smoking COPD patients. It can slow down the progress of the disease in smokers and decrease COPD-related deaths (WHO 2017). Pharmacological therapy is used to reduce symptoms, reduce frequency and severity of exacerbations, and improve exercise tolerance and health status.

The goal of AECOPD treatment is to minimize the negative impact of the current exacerbation and prevent the development of subsequent events (GOLD 2017). Depending on the severity of an AECOPD, it can be managed in either the outpatient or inpatient setting. In addition to pharmacological therapy, hospital management of AECOPD includes respiratory support, of which oxygen therapy is a key component. Further ventilator support can be provided by either noninvasive (NIV) or invasive ventilation (GOLD 2017).

Discharge planning and teaching is acknowledged as a crucial component in the efforts taken to reduce hospitalization, including readmissions (Abad-Corpa et al. 2012). Discharge from hospital is a multi-interventional process in which elements such as optimization of medication, education, supervision of inhaler techniques, and coordination of different kinds of activities such as follow-up, tele-monitoring, and rehabilitation activities are to be recommended (GOLD 2017). Early follow-up is recommended, and it has been found to be related to fewer exacerbation-related readmissions (GOLD 2017). Later follow-up should be offered, too, in order to reassess the treatment and the patient's ability to cope at home (GOLD 2017). Physical activity, training and self-management are recommended as an important part of the non-pharmacological treatment. Pulmonary rehabilitation has been shown effective to improve health-related quality of life and exercise capacity (McCarthy et al. 2015). Consequently, patients with high symptom burden and high risk of AECOPD should be encouraged to attend a full rehabilitation programme that includes these components (GOLD 2017).

The clinical pathway

The treatment and management of COPD in Denmark follows the GOLD recommendations, which are incorporated into national and regional disease management programmes that describe optimal COPD treatment and management (KKR & Region Sjælland 2016, Lange 2012). The clinical pathway is organized so that healthcare during hospitalization, follow-up and rehabilitation is provided in cooperation between general practice, hospitals (pulmonary clinics) and municipalities.

In the ongoing development and implementation of the above-described efforts both in Denmark and globally, the Chronic Care Model (Wagner 1998) has led the way and guided recommendations for an integrated effort within the organization and provision of healthcare concerning chronic illness, including COPD (GOLD 2017). In the following, selected aspects associated with this model are elaborated further.

2.5. Approaches to guide the organization and delivery of healthcare

Chronic Care Model

As a response to the growing challenges associated with healthcare of people with chronic conditions, the Chronic Care Model was developed by American experts back in 1990s and was intended to provide a tool for improving care at both the individual and population levels (Wagner 1998). The model represents a framework of integrated care that consists of six key elements. These elements focus on promoting high quality of care that is consistent with scientific evidence and patient preferences, mobilizing community resources, enabling patient self-management, effectively using clinical information systems, cultural competence, care coordination, and health promotion (Davy et al. 2015). At the heart of the model is an informed, activated patient and prepared, proactive healthcare professionals, who work together in order to achieve improved outcomes (Wagner 1998).

As regards the delivery of the treatment and care within the area of COPD, the principles of the Chronic Care Model are reflected explicitly in the global recommendations regarding the initiatives to support COPD patients' self-management. The importance of the collaborative approach to healthcare is pointed out in how support of self-management must be delivered in a way that enables iterative interactions between patients and healthcare professionals (Effing et al. 2016).

Patient participation in healthcare

As illustrated by the Chronic Care Model, patients with chronic illness are supposed to take an active role in the clinical decision-making with healthcare professionals (Wagner 1998). This requirement is translated by healthcare professionals to person-centred approaches that aim to ensure that healthcare delivery is respectful of and responsive to individual patient preferences, needs, and values, and that ensure that patient values guide all clinical decisions. Consequently, strategies are devised in order to engage, support and empower people with chronic conditions to manage their illness better (Coulter 2011).

Within the area of collaborative or participatory approaches to healthcare, patient participation is one of the many concepts that are brought into play, and sometimes interchangeably, with other activating approaches and strategies in clinical decision-making, such as patient involvement, user involvement, and engagement (Castro et al. 2016). According to Cribb (2011), who refers to the concept involvement in a report by the Centre for Public Policy Research, Kings College London, the importance of such an approach lies in the possibility of a “two-way” movement. In the same way as the patient enters into, and somehow participates in, the clinical sphere, clinicians can enter into, and participate in, the “non-clinical” sphere, such as the life worlds of patients (Cribb 2011).

To grasp a way to express this movement in this study, the term patient participation is used. The choice is made while different aspects of patient participation are thoroughly explored and interpreted in the hospital care context in which the study takes its starting point (Angel & Frederiksen 2015, Castro et al. 2016, Tobiano 2015, Tobiano et al. 2015, Tobiano et al. 2016a, Tobiano et al. 2016b). There is still no consensus about how to understand or define patient participation. According to a recent concept analysis and literature review, patient participation in hospital care can be defined as:

A patient's right and opportunities to influence and engage in the decision-making about his own care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional's expert knowledge (Castro et al. 2016, p. 1929).

Although this definition involves patient participation only, this study recognizes that those who engage and are included in this process can also include families. Moreover, in order to maintain simplicity throughout this thesis, the term patient is widely used. While the study took its starting point in the hospital setting, it was found appropriate to continue the usage throughout the study, in the knowledge that people with COPD living at home in the community setting might not consider themselves to be patients. The family member was whomever that the patient identified as being family.

The work of Castro et al. (2016) is remarkable for the way in which they derive a connection between three important concepts often introduced and used interchangeably within the area. Through their analysis of the concepts of empowerment, patient participation and patient-centeredness, they offer a framework, in which patient participation is understood as a strategy to achieve a patient-centred approach, which subsequently can lead to promotion of patient empowerment. Furthermore, they conclude that, through this process, there can be seen a movement from quality of care in hospital towards quality of life in society (Castro et al. 2016).

Thinking with this framework makes us more clearly understand the connection and movement between the delivered healthcare in the clinical setting, and the health-illness related decisions and activities, which can be associated with patients' management of their condition at home.

Self-management support

As previously stated, the Chronic Care Model and the recommendations for treatment and management of COPD, acknowledge support of patients' self-management as a way to empower and prepare patients to manage their health and healthcare (Wagner 1998, GOLD 2017). In the context of Castro et al.'s (2016) framework, the term self-management is not included directly, but indirectly, by noting that achieving self-management is one of the most oft-mentioned consequences of an empowerment approach. That is, self-management can be what is sought by patient and family participation in healthcare. Self-management is an umbrella term, but a frequently used definition is proposed by Barlow et al. (2002, p. 178):

Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established.

Accordingly, as the attention to achievement of self-management skills in patients with COPD has increased within the last decades, there has been considerable research on different aspects of self-management, outcomes and effects of supportive initiatives within healthcare. The potential benefit of self-management interventions has been shown in numerous studies (Bourbeau et al. 2013, Disler et al. 2016, Harrison et al. 2015, Jolly et al. 2016, Jonkman et al. 2016, Jonsdottir 2013, Zwerink et al. 2014). Yet, the picture of the evidence is unclear, and the family perspective is presented sparsely (Jonsdottir 2013). Likewise, Kaptein et al. (2014) argue that the previous interventions and research have been insufficient to meet the needs of both COPD patients and their families. Based on a review, they found that previous interventions have primarily been associated with a healthcare professional-centred approach, focusing on training patients, and primarily, on measuring outcomes such as hospital admissions and biomedical outcomes. In order to improve the future self-management support, they instead suggest that future interventions and research emphasize approaches, which, rather than educating, encourage the patients to take control of the illness, treatment and consequences. At the same time, they recommend a focus not only on outcomes, measured as functional status and quality of life, but also on how patients and family members make sense of their illness and its medical management (Kaptein et al. 2014).

Thus, there still seems to be a need to refine the strategies and approaches to support self-management within healthcare so that it is more centred on COPD patients' and their families' preferences and experiences. In this light, the clarification of concepts related to the Chronic Care Model and the framework presented by Castro et al. (2016) was drawn upon to guide and limit a further literature search and review.

2.6. Literature search and review

The above-described comprehensive burden of living with COPD and the ongoing efforts to improve healthcare within the area call for a further in-depth investigation of what is at stake for COPD patients and their family members when they go through a severe AECOPD, hospitalization and the time after, and have to participate in their own care over time.

The question is; what are their experiences of participation in care decisions and activities, both within and beyond the hospital context?

The in-depth approaches, which are used in qualitative research can allow for a better understanding of the lived experiences of illness, including the ways in which individuals interact

with the healthcare system and why they make specific healthcare choices (Grossoehme & Lipstein 2016). Therefore, a systematic literature search was conducted in order to achieve insight into the existing empirical qualitative research on these issues and to narrow down the focus of this study. The search was performed in CINAHL, Cochrane Library, MEDLINE and PsycINFO, prior to and throughout the study period – from 2014 to the final search in February 2017. The literature review was performed as a background review, which can be appropriate to identify the gaps or controversies that will be addressed in a study and to connect past research with the ongoing research (Sandelowski & Barroso 2007). In this review, this meant the connection of the past qualitative research with this study.

The systematic literature search was undertaken in accordance with principles as described in the SPIDER Tool for qualitative evidence synthesis (Cooke et al. 2012). Thus, the search was guided by search terms related to the sample, phenomenon of interest, design, evaluation and research type. Using this approach provides a way to build up a systematic search strategy suitable to the identification of topics and methods related to qualitative research (Cooke et al. 2012). In building the search strategy, search terms related to the sample, here, COPD patients and their family members, were determined. Next, search terms related to the phenomenon of interest were developed. In order to capture this the best as possible, terms were chosen that related to the above-described framework and concepts.

Finally, search terms related to designs appropriate to capture the patient and family perspective were used, search terms related to evaluation were formulated in terms of experiences and attitudes, and search terms related to research type were determined to qualitative or mixed methods. Table 1 presents the search strategy and results of the search.

The process of the literature search furthermore was based of the inclusion criteria: systematic review, original research, and English, Danish, Swedish and Norwegian language literature. The assessment of the literature started by reading headlines in results of searches with fewer than 1,000 hits. Of the total 657 hits, 422 hits were selected for further assessment. Subsequently, the abstracts and the full texts reading were read, followed by a chain search with use of criteria consistent with the search strategy. After this process, 20 hits were selected that were considered relevant to the focus of a further review.

Two of the papers presented, respectively, an integrated review and a meta-synthesis in which the included research papers had undergone an assessment of the quality. For the assessment of the quality of the other selected papers, the guide for appraisal of qualitative studies as proposed by Sandelowski & Barroso (2007, p. 83) was used. This meant that an assessment was made of whether the research problem and the aim were clearly stated. Next, it was assessed whether there was consistency between aim, methods, and the presented results. Finally, a judgement was made as to whether the results were discussed appropriately and whether implications for further clinical practice or research were made. As a result, included in the following review were only those studies that were found satisfactory according to these issues.

Table 1. Presentation of search strategy and results of the literature search

		MEDLINE	Embase	Cochrane Library	PsycInfo	CINAHL
SPIDER Tool	Search Terms	Hits	Hits	Hits	Hits	Hits
S - Sample	chronic obstructive pulmonary disease	64,443	11,647	7,271	1,131	9,026
P of I - Phenomenon of Interest	participat* OR involve* OR engag* OR attitude of healthcare professionals OR patient nurse interaction* OR collaborative care OR patient-centred care OR family-centred care OR professional family relations OR family nurs* OR family dynamics OR self-manag* OR self-care OR empower* OR hospital*OR admi*OR OR inpatient* OR exacerbation* discharge* OR follow-up* OR recover* OR transition*	4,977,466	17,115,927	42	1,137,315	1,390,865
S and P of I		459,117	3,646	42	404	1,695
D – Design	interview* OR observation* OR survey* OR questionnaire* OR focus group* OR case study* OR longitudinal*	2,344,253	4,813,889		127,735	551,510
E – Evaluation	experience* OR view* OR opinion* OR attitude* OR perce* OR belie* OR feel*OR know* OR understand*	3,236,778	15,134,573		28,735	583,464
D OR E		5,581,031	18,581,695		148,396	923,158
R – Research type	qualitative OR mixed method*	125,076	1,302		21,415	84,135
[S AND P of I] AND [(D OR E) AND R]		62	151	11	163	270

2.7. Literature review

In the following sections, a review of the selected studies is presented. The results are organized according to findings revealing experiences related to different contexts – with 10 papers regarding the hospital care setting, see Table 2, and 10 papers regarding the day-to-day care context at home, see Table 3.

COPD patients' and their family members' experiences related to their participation in healthcare in the hospital setting

According to Norwegian researchers, it is important that patient participation in care should be understood in relation to a specific setting and the interactions that occur in this setting (Kvangarsnes et al. 2013). Thus, in order to make a case for this study, several studies conducted in different settings and situations related to the hospital are presented in the following section.

Typically, the course of care related to a severe AECOPD comprises acute hospital care, stabilizing care during the recovery, care related to discharge planning and teaching, and care related to follow-up on discharge. Research conducted in the acute care setting showed that patients experienced extreme breathlessness, lack of power, dependence and feelings of being neglected by healthcare professionals as barriers to participation in their own care. In contrast, feeling respected and having trust in healthcare professionals could be linked to increased feelings of self-control (Kvangarsnes et al. 2013, Torheim & Kvangarsnes 2014). Other studies pointed to similar challenging perceptions during treatment with noninvasive ventilation (Sørensen et al. 2013), and during assisted personal body care (Lomborg & Kirkevold 2008, Jensen et al. 2013).

A study conducted on a medical ward indicated that lack of attention after the initial symptoms were stabilized, insufficient communication about care plans, and lack of coordination between primary and secondary sector could make recovery problematic (Bailey et al. 2016). Furthermore, family members reported experiences of stress associated with feelings of being insufficiently involved in their relative's care (Bailey et al. 2016, Bove et al. 2016). During follow-up outpatient consultations, patients presented challenges in not being adequately recognized by healthcare professionals in their needs for sharing their stories about issues related to their coping with illness or existential aspects of their everyday life (Jensen et al. 2015).

In another study, receiving personal attention in an atmosphere in which there is enough time taken for the person, apart from their illness, was stressed as important by COPD patients during consultations in the outpatient clinic and at their general practitioner's surgery. Moreover, they also revealed difficulties in talking about their own goals and troubles in self-management with healthcare professionals (Hillebregt et al. 2017).

To conclude, the experiences of limited participation in hospital care in particular at discharge and follow-up consultations seem critical while it might affect patients and their families in how they continue their self-management at home. The next section elaborates further on the experiences related to self-management, as they are unfolded in the selected empirical studies.

Table 2. Overview of the selected qualitative studies with focus on COPD patient and family participation in hospital care

Authors and year	Type of study/method	Sample/setting/country	Aim
Lomborg et al. 2005	Participant obs. in-depth interviews study of nurse-patient interaction	12 patients with severe COPD/ Medical wards in hospital, Denmark	To explore patients' experiences of being assisted with personal body care
Lomborg & Kirkevold 2008	Participant observations and in-depth interviews Grounded theory study of nurse-patient interaction	12 patients and 4 nurses/ Medical wards in hospital Denmark	To present a theoretical account of professional nursing challenges involved in providing care to patients suffering from COPD. The objectives are patients' and nurses' expectations, goals and approaches to assisted personal body care
Jensen et al. 2013	Participant observations and in-depth interviews Interpretive description method	11 patients/ Medical wards in hospital Denmark	To explore patients' experiences of receiving a patient-centred personal body care intervention and document changes compared to the patients' experiences in previous hospital stays
Sørensen et al. 2013	Participant observations and in-depth interviews Grounded theory	21 patients in non-invasive ventilation (NIV) observed and 11 interviewed after hospitalization Denmark	To present a theoretical account of the pattern of behaviour in patients with acute respiratory failure due to COPD while undergoing NIV
Kvangarsnes et al. 2013	In-depth interviews Narrative analysis	10 patients who had been admitted in Intensive Care Unit (ICU) Norway	To explore patient perceptions of COPD exacerbation and the patients' experiences of their relations with health personnel during care and treatment
Torheim & Kvangarsnes 2014	In-depth interviews Phenomenological analysis	10 patients who had been admitted in ICU Norway	To gain insight into how patients with advanced COPD experience care in the acute phase
Jensen et al. 2015	Field observations Interviews Grounded theory	43 patients 11 doctors 11 nurses In hospital-based outpatient respiratory medical clinics Denmark	To develop a theoretical framework explaining patients' behaviour and actions related to unmet needs during interactions with healthcare professionals in hospital-based outpatient respiratory medical clinics
Bailey et al. 2016	Critical incident case study Interviews Thematic analysis	39 patients: 15 with COPD and 24 with lung cancer 20 informal carers 50 healthcare professionals Hospitalization United Kingdom	To explore the experiences of patients with advanced COPD and lung cancer, their carers and healthcare professionals following emergency admission to acute care hospital
Bove et al. 2016	Qualitative Three focus group interviews Thematic framework	22 spouses of patients with severe COPD Denmark	To explore how spouses of patients with severe COPD experience their role as informal caregiver
Hillebregt et al. 2017	Mixed methods The qualitative part: Video observations Interviews Thematic framework approach to content and thematic analysis	46 patients with mild to very severe COPD 11 healthcare professionals Holland	To investigate possible effective facilitators of and barriers to the implementation of self-management in both general practices and their affiliated hospitals

COPD patients' and their family members' experiences of self-management at home

The overall picture of the selected studies was that the efforts made to self-manage the day-to-day care at home implied varied strategies and behaviours that were used to prevent, control, and manage or cope with the many effects of the COPD (Brien et al. 2016, Cicutto et al. 2004, Clari et al. 2017, Disler et al. 2012). However, a range of physical, psychosocial, existential, and provider-related factors was identified to influence and challenge the individuals' abilities and possibilities to self-manage (Cicutto et al. 2004, Disler et al. 2012). Management of respiratory symptoms and treatment dominated the daily tasks of self-management (Chen et al. 2008, Disler et al. 2012). In particular, self-management related to episodes of exacerbations presented challenges, which could be linked to feelings of fear and difficulties in how to act adequately, including when to seek help. In an investigation of the underlying process of exacerbation-related self-management behaviour, it was found that the perceived influence on the exacerbation course and the feelings of being self-empowered were of importance to whether active self-management actions that were taken, including when to seek help (Korpershoek et al. 2016, Williams et al. 2014).

The daily self-management was described as including self-regulation activities, in which for example emotional adaptation, maintaining a healthy lifestyle, and selecting suitable healthcare professionals could present a challenge (Chen et al. 2016). In addition, Wortz et al. (2012) identified that COPD patients' concerns about self-management could be of motivational character. This was evident in how fearful experiences associated with uncontrolled breathlessness could make patients highly motivated to avoid them and to learn about new medications (Wortz et al. 2012).

In order to deal with the many efforts related to self-management, help and support from relatives appeared to be important, but family members' participation in self-care could be both a positive source of support and a source to create a conflict (Apps et al. 2014). Moreover, help and support from healthcare professionals was mentioned as important, but various conditions could make the contact difficult (Clari et al. 2017, Disler et al. 2012).

In summary, the literature about COPD patients' efforts to self-manage points to a complexity in how to adjust to the ongoing and various changes throughout the treatment and illness trajectory. The literature furthermore indicates the importance of appropriate help and support from family and friends, and healthcare providers.

Table 3. Overview of the selected qualitative studies with focus on COPD patients' self-management

Authors and year	Type of study/research method	Sample/Country	Aim
Cicutto et al. 2004	Focus-group interviews Constant comparative analysis	42 patients Severity of COPD not reported Canada	To understand the day-to-day care activities of people living with COPD that takes into account their meaning of the activities
Chen et al. 2008	In-depth interviews Miles and Huberman's text analysis	18 men with mild to very severe COPD Taiwan	To explore the self-management behaviours of patients with COPD as a means to understand how patients manage their disease
Disler et al. 2012	Integrative review Includes the patient perspective	44 articles: 13 qualitative 10 descriptive, experimental or quasi experimental 6 reviews 15 discussion papers Several countries	To facilitate a review of the influences on self-management in COPD and to develop a conceptual model to illustrate it
Wortz et al. 2012	In-depth interviews Thematic analysis	47 patients with moderate to very severe COPD USA	To examine patients' responses to questions about goals, needs, and expectations regarding self-management
Apps et al. 2014	Interviews Thematic analysis	15 patients with mild to very severe COPD UK	To explore the self-care experiences of patients with COPD who are primarily managed in primary care, and to examine the challenges of engaging in such behaviours
Williams et al. 2014	Interviews Grounded theory	44 patients with moderate to very severe COPD UK	To explore patients' current understanding and experience of managing and identifying COPD exacerbations at home
Brien et al. 2016	Semi-structured interviews Analysis Comparative analysis	34 patients with mild to very severe COPD UK	To explore and understand variations in experiences and coping strategies in COPD patients across different severities of disease and disease impact
Korpershoek et al. 2016	Semi-structured interviews Grounded theory	15 patients with mild to severe COPD Holland	To identify and explain the underlying process of exacerbation-related self-management behaviour in COPD necessary for the development of future targeted and tailored interventions
Chen et al. 2016	Interviews Content analysis	18 men with mild to very severe COPD Taiwan	To explore self-management from the perspectives of patients with COPD
Clari et al. 2017	Review: A meta-synthesis Includes the patient perspective	14 articles Several countries	To identify, evaluate and synthesise the qualitative literature on the self-care behaviours and strategies used by people with COPD

2.8. Rationale for the thesis

As shown in the review of the selected qualitative studies, COPD patients can encounter various difficulties in having the requisite capacity and opportunity to participate in healthcare when they interact with healthcare professionals in the clinical setting and during their self-management at home. Nonetheless, family members' perspective on participation in their relatives' care in the hospital setting, in relation to discharge planning and to interventions to support self-management is sparsely explored. Moreover, research regarding experiences of interacting with healthcare professionals across settings, sectors, and over time after the hospitalization is limited.

The majority of the papers included in the background review present results related to time-limited contexts. The studies can therefore be considered to represent fragments of knowledge related to a person's position at a particular point in time. As pointed to by other researchers, such knowledge might be less suitable to embracing the changing illness experience linked to the nature of and various transitions through the treatment and illness trajectory of a chronic illness like COPD (Kralik & van Loon 2009). Thus, greater insight based on a longer and coherent period might be valuable to capture both COPD patients' and their families' evolving experiences related to their participation in healthcare over time.

Furthermore, considering the limitations in previous research highlighted above, and the remaining challenges to the implementation of effective COPD self-management interventions, a more nuanced picture of COPD patients' and family their members' concerns, considerations and efforts is still warranted.

Because of the overall burden of COPD there is still a need to explore what more can be done to and what more to emphasize when making strategies to engage, motivate, and support patients to better self-management of their day-to-day care and family members to better support them during the progression and exacerbations of illness.

Thus, the thesis presents a qualitative exploration of experiences in relation to a coherent part of the illness and treatment trajectory during and after hospitalization for a severe AECOPD. In order to nuance the current picture, the study thereby seeks to present the breadth and depth in the experience of living a life with COPD for both the patient and the family, when participating in healthcare.

3. Aim and research questions

This thesis aims to develop knowledge about the impact of living with COPD by exploring patients' and their family members' experiences related to their participation in healthcare during and after a hospitalization for a severe AECOPD.

Thus, it is the experiences in relation to participation in care decisions and activities at hospital and at home that make up the underlying basis for insight in the meaning of dealing with own care to COPD patients and family members.

The following research questions guided the study:

- How do COPD patients experience their participation in healthcare pre-discharge and post-discharge? (paper 1)
- How do both COPD patients and their family members experience participation in healthcare around discharge from hospital and in the subsequent day-to-day care at home? (paper 2)
- How do COPD patients and their family members experience their interactions with healthcare providers post-discharge? (paper 3)

The intention of the thesis was to add to the research within the area of COPD in order to improve the quality and contribute to the development of the clinical pathways in relation to patients with COPD and their families.

4. Scientific framework

The results in this thesis are derived through a qualitative research approach. When planning and implementing qualitative research, Carter & Little (2007) argue that it is important to clarify the three fundamental facets of research – epistemology, methodology, and methods - and be aware how they relate to each other (Carter & Little 2007). In line with this, the following reveals the considerations made about how these facets and their interrelationship have guided this study.

4.1. Epistemology and methodology

Epistemology can be understood as the theory concerned with the nature and justification of the knowledge that is sought (Carter & Little 2007). According to Carter & Little (2007), philosophies, formal theories and praxis of social inquiry can form the epistemology within qualitative research. This study draws on phenomenology and hermeneutics as its underlying philosophies. This means that the thoughts related to these philosophies have influenced each step in the research process.

The French philosopher Paul Ricoeur's (1913-2005) thinking around phenomenology and hermeneutics has been a determinant in the epistemology applied in this study (Dreyer & Pedersen 2009, Ricoeur 1976). Carter & Little (2007) explain it in such a way that epistemology modifies methodology and that methodology justifies, guides, and evaluates methods. A methodology is related to issues around the assumptions, principles and procedures in a particular approach to inquiry (Carter & Little 2007).

The methodological issues in this study relate to the approach to inquiry taken by Ricoeur in his work around narrative and interpretation (Dreyer & Pedersen 2009, Ricoeur 1976). Ricoeur's work has been translated widely, and discussed across the world. Throughout his career, he was noted for entering into dialogue with many philosophic disciplines and philosophers. His extensive philosophy combines Greek tradition with German traditions, and Anglo-Saxon philosophy of language and structural linguistics (Ricoeur et al. 2002). Ricoeur is considered to be the bridge-builder between phenomenology and hermeneutics. The phenomenological thinking of the German philosopher Husserl formed the basis of his philosophy, but over time he found that the descriptive approach did not relate to the phenomenology sufficiently enough to understand human action and life, and therefore combined it with hermeneutics and a philosophy of language (Ricoeur et al. 2002).

Within the last two decades, Ricoeur's philosophy and theory about narrative and interpretation has inspired much research within nursing. Particularly in northern European countries, nursing researchers have developed methods to catch the voice of patients or other users of healthcare (Dreyer & Pedersen 2009, Hounsgaard et al. 2007, Lindseth & Norberg 2004). The study presented in this thesis leans on this approach, while it is found appropriate to develop new and useful knowledge with implications for further development of clinical practice, education, and research.

4.2. Phenomenology and hermeneutics

Phenomenology concerns with the investigation of phenomena revealed by the lived experience. According to Husserl, the original experience is a basic relatedness to the world. The human consciousness is intentional and implies an openness to the world, the life-world, which should be understood as the way that the world reveals itself to our consciousness (Lindseth & Norberg 2004). In order to grasp the inner experience of the human being, Husserl furthermore

introduced the concept phenomenological reduction (Ricoeur et al. 2002). By this, Husserl stressed that we must take an attitude in which we accomplish "bracketing" (epoché). This means that we must refrain from making judgments about the factual and therefore seek solely to describe the experiences to constitute the essential meaning of what appears or put in another way the phenomena that are disclosed (Ricoeur et al. 2002). Throughout this study, the phenomenological approach implied that thick descriptions were sought of what the participants experienced and saw as meaningful in their life world.

Ricoeur was critical of Husserl's thinking about reduction and he therefore supplemented it with thoughts of a critical hermeneutic (Ricoeur et al. 2002, Ricoeur 1976). If grasping the meaning of the lived experience should be possible, Ricoeur found that interpretation of the descriptions of lived experiences is necessary. In this case, he was highly inspired by the German philosopher Gadamer (Ricoeur et al. 2002). Gadamer did not find it possible to put prejudices and preconceptions aside and meant that they had to be put into play in order to achieve new understanding. In this sense, Gadamer spoke about the need of fusion of horizons to achieve enhanced understanding (Gadamer 2004). According to him, acquiring a new horizon means that one has to look beyond what is close at hand – not in order to look away from it but to see it better, within a larger whole and in a truer proportion (Gadamer 2004).

In hermeneutics, the language and the way in which society is experienced, plays a central role (Pedersen 1999). Ricoeur applied theory of language and discourse to his thoughts about the critical hermeneutic. He saw language and the conversation as the space in which our culture is created, and was concerned with aspects that are not directly to be explained, nor do they seem rational. He furthermore thinks that it is only in activities together with others that one's own existence is experienced. Hermeneutics then is not merely a theory of an interpretation method but rather a question of what role the interpretation has for the cognition of the self and the world (Bruun 2010, Pedersen 1999). As this study wants to provide insight into COPD patients and their family members' experiences and interpretations of their life during hospitalization and in an everyday life with chronic illness, the following addresses how, through narratives, it becomes possible to get insight into a part of their lifeworld.

4.3. The narrative as the background to achieving data in the study

Central to Ricoeur's thoughts about the narrative is that he argues for its capacity to represent the human experience over time. This means that the existence is developed through the narrative language (Wood 1991). Ricoeur put it this way: *"A life is no more than a biological phenomenon as long as it has not been interpreted"* (Wood 1991, p. 28). Accordingly, the narrative originates from the lifeworld and the purpose is to affect this world in order to better understand one's own situation, and to orientate oneself and act in this world (Pedersen 1999). Inspired by the Greek philosopher Aristotle, Ricoeur applied the thinking of the threefold mimesis to his understanding of hermeneutics and interpretation. According to Hermansen & Rendtorff, drawing on the threefold mimesis can be considered an epistemological tool to understand the immediate human action and life (Ricoeur et al. 2002, p. 22). The threefold mimesis comprises a process on three levels to understand textual compositions about human action and life in a time-related course (Kemp 1999). Ricoeur describes it as a process by which the textual configuration mediates between a prefigured time and a refigured time (Ricoeur 1984).

Mimesis 1 is the first stage, representing the stage of prefiguration. Prefiguration can be understood as the pre-narrative stage of understanding. It is in one's preconception of the practical life that it becomes possible to grasp the meaning of the narrative (Kemp 1999, Ricoeur 1984).

Mimesis 2, the second stage in the process, denotes the configuration of the narrative. The configuration implies the creating and shaping activity in which the plot is composed (Ricoeur 1984). Thus, the configuration expresses the idea, the point or the theme that the narrative tells about, when it is recalled or recounted (Kemp 1999).

In mimesis 3, the refiguration takes place. The refiguration is about the reception of the narrative. In this last stage, the reading allows the reader to appropriate the text and to be moved by the narrative (Kemp 1999, Ricoeur 1984). Through the narrative, a new world has been disclosed and a new understanding made possible (Ricoeur 1984). Hence, while human beings will always use language to say something about something, what is said will have a reference to the reality or world about what is being spoken about (Ricoeur 1976). The text will only provide meaning if it is appropriated and actualized in the actual situation (Pedersen 1999).

In this study, mimesis 1 was expressed in how the participants understand their life with illness and their encounters with healthcare services. Mimesis 2, the stage of configuration was unfolded in how the participants revealed their experiences and actions in different situations throughout the study. In mimesis 3, attempts were made by the researcher to achieve enhanced understanding and add new perspectives to the focus of the study. In the process of understanding the participants' experiences and actions, Ricoeur's theory of interpretation is used and the process is presented further in the following section.

4.4. Interpretation of texts

Transforming narratives to texts is a way to make them available for a process of interpretation. For Ricoeur, a text is understood as discourse, which has been fixed through the writing (Ricoeur et al. 1988). Ricoeur argues that the fixation of the text replaces a spoken discourse. A text calls for reading. In reading, though, the text has left its author and a dialogue between the reader and the author has become absent. However, all texts have a reference to something in the world, and it is in the interpretation inherent in the reading that the reference is made actual (Ricoeur et al. 1988).

Ricoeur discusses the duality of reality presented in a text – the real world versus the experienced world, objectivity versus subjectivity (Pedersen 1999). He furthermore points to a dialectic between that distancing and the appropriation of the text – or between the writing and the reading (Ricoeur 1976). In the appropriation of the text, the reader makes it her own.

In this process, a dialectic movement is present between explanation and understanding and between the parts of the text and the whole of the text, which can be described as a movement of a spiral (Ricoeur 1976). Hereby, it is sought to grasp the sense of the text, which can be understood as what opens up in front of the text: *"To understand a text is to follow its movements from sense to reference: From what it says to what it talks about"* (Ricoeur 1976, pp. 87-88). As stated by Ricoeur, a text allows for more than one interpretation and it is always possible to argue for or against an interpretation. However, not all interpretations can be considered equal. The interpretation is based on a guess and cannot be verified, but must be discussed in relation to what we know on the basis of a logic of probability (Bruun 2010, Ricoeur 1976). Ricoeur (1976) applies three levels to the interpretation process, which encompass a movement from a naïve reading to explanation and from explanation to an enhanced level of understanding. The way in which this unfolded in this study is described in relation to the actual analysis method (p. 35).

4.5. Fieldwork

An ethnographically inspired fieldwork was applied as a complementary methodology in this study. Fieldwork is the process by which researchers seek to describe and reach an enhanced understanding of a culture (Polit & Beck 2006). Former research within nursing science has shown that the narrative in which lived experiences are expressed and interpreted can play a central role in coming to understand better the culture within a group of people who are in a particular situation (Hounsgaard 2004).

Following COPD patients and their family members in a fieldwork made it possible to achieve realistic accounts and outline their experiences related to their individual pathways and everyday life at home (Hounsgaard 2004). The American anthropologist James Spradley inspired the approach used in the fieldwork in the study (Spradley 1980). According to Spradley, fieldwork explores culture in social situations. He defines a culture as *"the acquired knowledge people use to interpret experience and generate behaviour"* (Spradley 1980, p. 6). A social situation includes a place, actors, and activities (Spradley 1980). The social situations in this study related to places or settings in the hospitals and private homes, and to healthcare professionals, patients and family members as actors. The activities in focus at hospital were those in which the patients and family members were involved as part of the treatment and care, together with what could be characterized as their daily life activities as inpatients. Which social situations should be under investigation were not decided in advance, but were adjusted to what was possible and relevant in the participants' individual treatment and care pathways. At home, the activities were limited to the interviews.

Spradley (1980) states that any culture consists of explicit and tacit knowledge. Then, to get an insight into what people know, it is up to the ethnographer to listen carefully to what they say, observe their behaviour, and study their artefacts and their use (Spradley 1979, Spradley 1980). As an attempt to capture this, participant observations and ethnographic interviews were here used as tools in a reflexive research process. By using these two tools as methods, it becomes possible to let them complement each other; in this case, the participant observation opened up questions for the interviews and vice versa (Hounsgaard 2009).

4.6. Participant observation

During participant observations, the researcher can choose to have different degrees of involvement. The researcher can act from being non-participating and observing to being more involved in activities together with the participants (Spradley 1980). In this study, the aim was to achieve a close balance in the social situations under investigation. The approach taken during conversations between patients, family members and healthcare professionals was as non-involved as possible, while the approach was more active at other times; for example, when together with the participants in waiting rooms or in the hospital dayroom. Moreover, Spradley (1980) put forward that informal interviews could be used during the course of participant observation as a way to establish and maintain good rapport and to ask the participants to elaborate on their experiences.

In line with Spradley's (1980) recommendations, three types of participant observations were used to capture the topic under investigation. Initially, in order to get an overview of the social situations in the field, the participant observations are descriptive. During a reflexive process, the participant observations become gradually more focused for thereafter to become more selective (Spradley 1980). According to the area in focus in the study, the participant observations over time focused on the social situations related to the discharge and gradually to selected aspects associated with participation in healthcare.

Doing fieldwork in the way described above represents a systematic way to collect data in a field. What was observed and experienced in the study was documented in field notes. As outlined by Spradley (1980), field notes can be undertaken according to nine dimensions of the social situation. This means that, at first, the focus is on space, actor and activity, which then are supplemented with records on the related activities, objects, acts, events, time, goal, and the emotions felt and expressed.

4.7. Interview

The ethnographic interview, which is defined by Spradley (1979) as a speech event, is an open interview form that takes the same approach as described above: it moves from being descriptive to focused and selective. Distinctive features of the interview are that it is formal and that it has an explicit purpose, which the interviewer must clarify to the interviewee each time they meet (Spradley 1979).

In this study, this approach was found suitable to make a conversation possible between the interviewer and the participants about how they saw their situation and what was significant to them. In the light of Ricoeur (1984), this can be understood further, while as he puts it, a speech implies a discourse, which is carried by the voice. An important aspect of the discourse is that it is directed at someone. The conversation is carried by the persons who speak and are together in the speech situation. It is then, in the reciprocity that lies in the exchange of the voices, that a common constitution of meaning and significance will appear (Ricoeur 1984). Ricoeur argues that every discourse is produced as an event in a dialectical way, as the relationship between event and meaning (Agerskov 2015, Pedersen 1999). Via the recounted, the something experienced moves from the speaker to the listener. Thereby, the experienced becomes public to the listener (Agerskov 2015, Pedersen 1999, Ricoeur 1976). The intention of such an exchange of meaning is to understand something that is different from ourselves and through that, to understand ourselves better (Pedersen 1999). Furthermore, Ricoeur points out the significance of symbolic and metaphorical language, which can contribute to achievement of enhanced understanding (Ricoeur 1976).

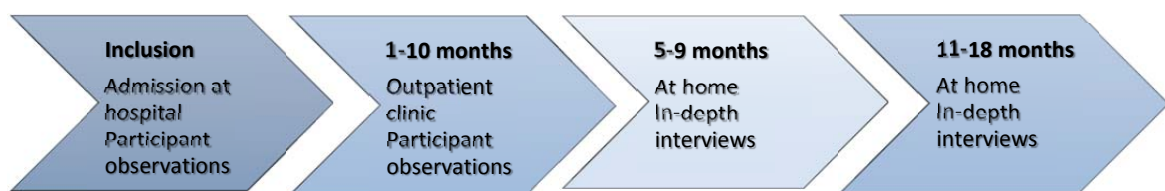
4.8. Design

A qualitative longitudinal and explorative design was chosen for the study to develop knowledge about the experiences involved during hospitalization and in the transitional time after a severe AECOPD. The wish to shed light on the lived experiences of illness, including the ways in which patients and family members self-manage and participate in healthcare through a period made a longitudinal and explorative design suitable. A qualitative study becomes longitudinal when its field work progresses over a long time (Saldaña 2003). During that time, it becomes possible to focus on how people think, feel, and act from moment to moment and thereby to capture in-depth perceptions and meanings. Additionally, it enables a better understanding of how human actions and participant perspectives might change during the course of the study (Saldaña 2003).

In this study, taking such an approach enabled exploration of development, pattern, and experiences from the same group of patients and family members over time – from a hospitalization until 18 months after a severe AECOPD. This meant that the participant observations and interviews were conducted repeatedly. According to Scottish researchers, serial interviews are suitable for the investigation of evolving and complex processes. Among others, they used the approach to identify the needs and service use of COPD patients, their family, and professional carers over a period of 18 months (Murray et al. 2009, Pinnock et al. 2011).

Moreover, a Swedish study has found that a similar design with repeated interviews over an eight-month period offered the opportunity to reach a deep layer as well as broader aspects in patients with severe COPD using long-term oxygen therapy and their partners (Ek et al. 2011a, Ek et al. 2011b). Ek et al. (2011a) argue that repeated interviews and a phenomenological-hermeneutic approach can be suitable in this process. While COPD patients often have difficulties in talking, meeting them more than once can be valuable by giving them more time to tell their story without stress (Ek et al. 2011a). Based on the experiences from these studies, and limited by the time available for the study, the study period was planned to last for 12 months. However, several circumstances related to the participants' situations meant that some of them were followed up to 18 months. Figure 1 illustrates the study flow.

Figure 1. Presentation of the study flow



Furthermore, by making the choice of taking both a patient and family perspective in this study, the intention was to get a more nuanced understanding of the complexity of the lived experience of COPD. Based on their research within the COPD area, the Scottish researchers state that research that uses more than a single perspective can contribute with knowledge about the relationships and dynamics among the parties under investigation, including similarities and differences in their mutual perception (Kendall et al. 2009). By combining a longitudinal approach with two perspectives, the hope was therefore to provide knowledge of both a broad and deep character.

4.9. Reflections on the research process

Through the fieldwork, it was possible to be together with the participants at several times and occasions and to follow them over a coherent period. The author of this thesis was the researcher in the field, and the approach taken can be compared to the approach of a traveller (Kvale & Brinkmann 2009). Hereby, the researcher becomes an explorer and a co-creator of the data (Hounsgaard 2009). It is, then, essential that the researcher meet the field in an as open-minded a way as possible. Since the researcher acts like her own tool in the research process, ongoing reflections related to the pre-conceptions and role as a researcher are crucial (Hounsgaard 2004). Accordingly, the background knowledge gained from the initially-conducted literature search and the clarification of concepts related to participation in healthcare and self-management necessarily contributed to the researcher's pre-conceptions. Furthermore, the researcher's background as a skilled nurse in clinical practice in the hospital setting meant that she strove to be aware of her pre-conceptions and to make this explicit at each step of the research process.

According to Wadel (1991), observation and participation are two separate processes, which take place at the same time through fieldwork. While participation involves an approach in which the researcher identifies herself with the participants' life experiences, observation implies that the researcher wishes to remain at a certain distance (Wadel 1991). For the researcher in this study, this meant navigating between the closeness that arose between her and the participants through the study period and the distance that could be required at

hospital, for example when the participants became breathless and needed to rest. Furthermore, Wadel (1991) suggests that the researcher must be able to adopt different complementary roles when doing fieldwork in her own culture. In this sense, he points to the usefulness of applying the role of apprentice to the researcher in order to achieve access to knowledge about a culture (Wadel 1991). While the intention was to learn from the participants in this study, the researcher attempted to be an apprentice in the participants' lives and context.

What is presented here represents only some of the reflections made in relation to how the research process was approached. Further considerations are described below in relation to each kind of method.

5. Methods

The methods constitute the research activities that were justified and guided by the methodology (Carter & Little 2007). Thus, guided by the methodological approaches and considerations presented above, the section below describes characteristics of the setting, the sampling and the sample, the data collection, and how the data analysis and interpretation were performed.

5.1. Setting

The first part of the study took place in a Department of Respiratory Medicine at a regional acute hospital in rural Denmark. The department consisted of a ward with 27 beds and a respiratory outpatient clinic. During her contact with the hospital, the researcher met the participants on several occasions throughout the clinical pathway, from admission onto the ward to visits at the outpatient clinic. The clinical pathway differed between the patients and, therefore, the study proceeded differently from patient to patient. Subsequently, the participants' own homes constituted the setting for the part of the study that was concerned with the follow-up on the clinical pathway initiated at hospital.

In the department in which the study was conducted, the clinical pathway is organized so that, after being stabilized in an acute care or intensive care setting, if necessary, patients are transferred to the respiratory medical ward for further treatment, stabilization and follow-up on discharge. The follow-up on discharge is tailored to individual needs. Typically, patients are offered both early and later follow-up visits in the respiratory outpatient clinic. The state of illness, need for tests and medical treatment are issues taken into consideration in the planning of follow-up. On at least one occasion, patients with COPD in a severe degree are offered participation in an in-hospital rehabilitation programme. After discharge, patients are typically followed up further by their general practitioner and maybe by different kinds of targeted healthcare services in the community.

5.2. Sample

With regard to the sampling, the patients were recruited consecutively during hospital admission to the respiratory ward. They were included based on inclusion criteria: doctor's diagnosis of COPD, hospitalized due to an AECOPD, Danish-speaking, and having a close family member involved in care. The family member should be the person whom the patient identified as being a family member. Exclusion criteria were: patients with other major diseases, such as malignancy or severe heart failure, dementia, medically unstable or palliative care patients.

In cooperation with the local staff, the inclusion of the participants took place over 35 days, evenly distributed over a period of six months from September 2014 to February 2015, after the acute phase of the AECOPD was stabilized. The 35 days were those days on which the researcher was unoccupied and able to include participants. For example, new participants were not enrolled on days on which the researcher was occupied with participant observations. In order to be able to follow the participants as much as possible and in a relevant way, the researcher largely chose to focus on one patient and family member at a time. In total, 116 patients were screened in accordance with the inclusion criteria.

Although stabilized from the acute episode of AECOPD, breathlessness, fatigue, and anxiety among the patients on the ward presented major challenges to inclusion. Living alone and not having close family members involved in daily care was another essential barrier to inclusion. Of the 16 eligible patients, 15 patients accepted. The family member was enrolled during the hospitalization or just after discharge, at the request of the patient. As the study proceeded, the principles of purposeful sampling were employed to achieve the best possible diversity among participants and thereby to achieve great nuances in the experiences that they disclosed (Polit & Beck 2006). In this study, this meant that patients were sought to represent the best possible variation in stage of illness, gender and age.

Table 4 lists characteristics for included patients and family members. In total, 10 women and 5 men, with an age range of 55 to 87, and with disease baseline severity ranging from mild to very severe COPD, were enrolled. The present AECOPD hospitalization placed all patients in GOLD group D (GOLD 2017), implying a high risk of hospital admission and death. One of the patients was too breathless to perform a spirometry. All had at least one comorbidity. Additionally, all had been hospitalized previously one or several times for a severe AECOPD. Four patients lived alone but with grown-up children living close by, nine lived together with a spouse and two patients lived together with grown-up children. In three cases, nominated family members initially gave verbal acceptance of participation in the study; however, as they were not present during the data collection at hospital, and as one became severely ill and two could not find the time to participate further, they were not included. Nevertheless, the patient participants were kept in the study, because they could contribute information about having family members involved in their care. Moreover, 12 grown-up family members participated in the study. Eight of the family members were spouses who lived together with the patient. Five of the spouses were women and three were men. Four family members were daughters, all of whom lived near the patient.

Based on previous research, it can be argued that limiting the number of participants in longitudinal qualitative studies reduces the risk to achieve too much data and thus losing the overview (Morse 1993). In the light of this, the total of 27 participants was assessed as an appropriate number.

Table 4. Baseline demographics of the participants.

Patients											Family members			
n=15	Gender	Age	Classification of COPD*	Impact of COPD CAT Score (COPD Assessment Test)**	Comorbidity Charlson Index of comorbidity Score***	History of admissions****	History of re-admissions*****	Cohabitation status	Smoking status	Profession	n=12	Gender	Relation to the patient	Living with the patient
P1	Female	73	2, D	16	1	No	No	Married	Ex	Retired	F1	Male	Spouse	Yes
P2	Female	56	3, D	17	1	No	No	Single	Ex	Unemployed	-	-	-	-
P3	Female	55	2, D	11	1	No	No	Single	Ex	Retired	-	-	-	-
P4	Male	67	4, D	25	4	Yes	Yes	Married	Ex	Retired	F4	Female	Spouse	Yes
P5	Female	68	3, D	18	2	No	No	Married	Ex	Retired	F5	Male	Spouse	Yes
P6	Male	77	2, D	15	2	No	No	Married	Ex	Retired	F6	Female	Spouse	Yes
P7	Male	68	-	-	5	No	No	Married	Ex	Retired	F7	Female	Spouse	Yes
P8	Female	72	2, D	15	2	Yes	Yes	Single	Ex	Retired	F8	Female	Daughter	No
P9	Male	74	3, D	25	5	Yes	No	Married	Ex	Retired	F9	Female	Spouse	Yes
P10	Female	74	3, D	29	2	Yes	No	Widowed	Ex	Retired	F10	Female	Daughter	No
P11	Female	87	2, D	18	1	No	No	Widowed	Never	Retired	F11	Female	Daughter	No
P12	Female	73	3, D	19	1	Yes	No	Married	Ex	Retired	-	-	-	-
P13	Female	65	1, D	17	1	No	No	Single	Ex	Retired	F13	Female	Daughter	No
P14	Male	69	3, D	23	1	No	No	Married	Ex	Retired	F14	Female	Spouse	Yes
P15	Female	63	3, D	10	1	Yes	No	Married	Ex	Retires	F15	Male	Spouse	Yes

* Classification of COPD: Scale 1-4, higher scores indicate greater severity of airflow limitation; Group A to D, D indicates the highest symptom burden and risk of exacerbation (GOLD, 2017)

** CAT: Scale 0-40, higher scores indicate worse patient-reported quality (GOLD, 2017)

*** Charlson index of comorbidity: Scale 0-31, higher scores indicate more comorbidity (Charlson et al. 1987).

**** History of admissions for AECOPD during the study period (excluding the admission when the patient was included)

***** History of readmissions for AECOPD during the study period

5.3. Data collection

Data collection was performed over 18 months, from September 2014 to February 2016. Because of the flexible design of the study, the study period and number of series of participant observations and interviews varied among the participants. The author of this thesis carried out the fieldwork, which took place at 21 admissions, of which two were readmissions within 30 days; the fieldwork is based on experiences gained from in total 53 hours of participant observations and 22 interviews conducted with 15 COPD patients and 12 of their family members. Four of the patients were followed during eight visits to the outpatient clinic, and one patient was followed at five sessions on a hospital-based COPD rehabilitation programme. The in-depth interviews were mostly conducted in the participants' homes, twice after about six months and 18 months since inclusion, except for two, which the participants wanted to take place at hospital.

The individual study periods ranged from four days to 18 months. Table 5 and Table 6 provide an overview of the individual courses for the participants and types of contact through the data collection process. Although a study period of 12 months had been planned, it became necessary to modify this according to circumstances in the individual participants' lives. The researcher followed all participants when they were in contact with the hospital, and some were visited once or twice at home. In between, iterative informal telephone conversations were held, as an initiative to keep in touch with the participants throughout the study. In total, 10 patients and 5 family members completed. During the study, 3 patients died, 2 patients dropped out, and 7 family members dropped out. With regard to the two patients who dropped out, one did not feel that she had sufficient energy to be interviewed and it was not possible to contact the other. The occurrence of severe illness, lack of time, or not being contactable were reasons for family members' drop out.

Table 5. Overview of the patients' individual pathways during the study

Year	2014				2015												2016	
Months	09	10	11	12	01	02	03	04	05	06	07	08	09	10	11	12	01	02
P1	I		O		O					IW1							IW2	
P2	I		O						IW1		O						IW2	
P3		I	Drop out															
P4	I	A							IW1									IW2
P5		I							O		O+							IW2
P6		I									O+						IW2	
P7		I						Death										
P8			I	A						IW1							IW2	
P9			I							IW1							IW2	
P10				I				Death										
P11				I						IW1							IW2	
P12				I							A	Drop out						
P13				I						IW1			O/ R	R			IW2	
P14					I							Death						
P15					I			A		IW1	A						IW2	

I = Inclusion during admission + participant observation;

A = Admission + participant observation;

O = Outpatient clinic+ participant observation;

R = Rehabilitation program + participant observation;

IW1= First interview at home/hospital;

IW2 = Final interview at home/at hospital

Table 6. Overview of the family members' individual pathways during the study

Year	2014				2015												2016	
Months	09	10	11	12	01	02	03	04	05	06	07	08	09	10	11	12	01	02
F1	I		O		O					IW1							IW2	
F4	I	A							IW1									IW2
F5		I							O		O+							IW2
F6		I	Drop out															
F7		I							IW1	Drop out								
F8			I	A	Drop out													
F9			I							IW1							IW2	
F10				I	Drop out													
F11				I	Drop out													
F13				I	Drop out													
F14					I						IW1	Drop out						
F15					I			A		IW1	A						IW2	

I = Inclusion during admission + participant observation;

A = Admission + participant observation;

O = Outpatient clinic + participant observation;

IW1= First interview at home/hospital;

IW2 = Final interview at home/at hospital

5.4. Participant observation

The participant observations and informal interviews were conducted with all the participants in series during the patients' stay at hospital, visits to the outpatient clinic, and during training sessions in the hospital-based rehabilitation programme. The nominated family members participated if they spontaneously visited the patient during admission or accompanied the patient to the outpatient clinic. Initially, the researcher followed the patients in the social situations that naturally occurred in the daytime and in the evening, one or two days before the planned discharge. The duration of each series of participant observations was from 20 minutes up to four hours, depending on the situation in focus. The variation in time was due to the fact that the patients now and then still suffered from distinct breathlessness and fatigue, and therefore, the amount of time used together was sought to be balanced in such a way that the presence of the researcher did not stress them unnecessarily. Unless agreed in advance, it was chosen not to be present for longer periods of time during the family members' presence. One reason for this was the wish to make space for privacy for the participants.

As the study proceeded, growing emphasis was put on how the participant managed to participate in activities and decisions about their care near discharge and during the subsequent follow-up visits. Through these activities, the researcher changed the level of participation. For example, in being largely observant during interactions between the participants and healthcare professionals, the researcher afterwards invited patients to describe how they perceived the situation (Wadel 1991). In that way, the approach shifted from being descriptive to being more focused (Spradley 1980). Gradually, the participants' experiences from previous admissions, readmissions, and concerns about being prepared to look after themselves at home became evident. Consequently, by asking the participants to elaborate further on their challenges, the participant observations became selective (Spradley 1980).

Field notes were taken as soon after the participant observations as possible. As a way to be able to recall during the fieldwork, brief notes or jottings were written in a little notebook in immediate continuation of the participant observations (Emerson et al. 2011). Direct quotations from the participants were also noted in some observations. After the fieldwork was conducted, the researcher went back to a desk and strove to write up the notes in a comprehensive text on the same day. This gave the opportunity to reflect on the information provided from the participants and the research process (Emerson et al. 2011). Going through this process enabled the researcher to develop her knowledge of the participants' life and context, and thereby gradually to become more focused and selective.

5.5. Interviews

The in-depth interviews were undertaken on one or two occasions after discharge with 10 patients and seven family members in the middle, and with 10 patients and five family members at the end of the study period. Interviews took place in the participants' own homes, apart from two that were held at the hospital. As intended, being at home seemed to make the participants more comfortable and free to speak in a way that was different than in the hospital setting. Ten of the in total 22 interviews were held jointly with patients and family members and twelve separately. Whether the interviews were joint or individual was a decision made by the participants, and in some cases, the decision was made based on practicality. Through the course of the study, the interviewed participants were met in situations where they either were alone or in situations in which patients and family members interacted together. This made it possible to achieve a wide range of dynamic perspectives on their life situation.

The atmosphere around the interviews was open and friendly and, in most cases, the participants invited the researcher to have a cup of coffee in the living room. This paved the way for a positive interaction between the participants and the researcher and stimulated the participants to tell about their experiences and feelings (Kvale & Brinkmann 2009). During the interviews, the focus moved from descriptions of how the participants managed their daily care to increased focus on more specific and sensitive concerns. In order to ensure that information about the topic under investigation was captured and to make space for new perspectives, the interviews were led by a semi-structured interview guide, see Appendix C. Inspired by recommendations for conducting ethnographic interviews, descriptive questions were combined with structural and contrast questions (Spradley 1979). The opening descriptive questions could be about how the participants experienced that their life situation had changed since the last contact with the researcher. Examples of the subsequent structural questions were "Tell me about how you manage your daily care", and "How do you feel supported?" The purpose of contrast questions is to clarify how the participants distinguish between things and events in their life (Hounsgaard 2009). An example could be "Tell me about the difference it makes to you to participate in your own care during hospitalization and at home" or "What difference does it make to receive support from healthcare professionals at hospital and in the community?" In accordance with Hounsgaard (2004), the use of this technique enabled insight into how the participants structured their experiences and made sense of their daily life.

The interviews varied in duration from 14 to 95 minutes. The interviews were documented by digital recordings and subsequently transcribed verbatim by the researcher.

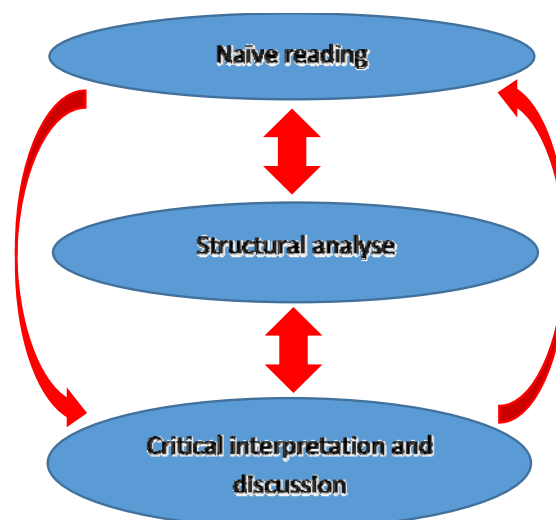
5.6. Data management

Research data are the pieces of information obtained in a study (Polit & Beck 2006). All the pieces of data – in this study, field notes and interview transcripts – comprised the entire data set. In order to organize the data, the whole data set was transferred to the NVivo version 10 software programme for qualitative analysis (QRS International Pty Ltd, Cheshire, UK). The systemization of data in NVivo was a helpful way to prepare for the further process of analysis and interpretation.

5.7. Data analysis and interpretation

The analysis and interpretation of the data in the study, here texts transformed from field notes and interviews, were conducted with the application of the Ricoeur-inspired method on three levels: naïve reading, structural analysis, and a critical interpretation and discussion. Below, Figure 2 illustrates the three-level analysis process.

Figure 2. Illustration of the three analytical levels of interpretation



In the naïve reading, the entire text material was read in a non-judgmental and open-minded way several times to obtain an initial understanding of what the text was about (Ricoeur 1976, Pedersen 1999). Through the readings, the researcher sought to understand the text by following what moved her and by entering into a dialogue with the text (Bruun 2010). This level had the character of guessing, while remaining open to the questions that began to arise from the text (Pedersen 1999). In order to keep hold of what moved the researcher and made her wonder, the initial impressions of the participants' lifeworld were written down in a text, in preparation for the further structural analysis.

The second level consisted of a structural analysis that aimed to open up the whole text and allow for a further interpretation of the participants' experiences (Pedersen 1999). At this level, a primary interpretation was performed by reading and dividing the whole text into meaning units. Concretely, this was done by identifying quotations in the text material ("what is said") that illuminated the same meaning.

Next, units of meaning with the same content of significance (“what the text speaks about”) were extracted. Thus, at this level, the analysis took place in a process that moved from what is said to what the text speaks about to the further emergence of patterns, subthemes and main themes. This process was carried out by constant reflexivity and ongoing internal validation of themes in relation to the naïve reading, units of meaning and units of significance.

In an attempt to manage better the extensive data set in the structural analysis, the successively gathered data were divided into two parts: the first part (part 1) consisted of the field notes referring to what was called “the hospital phase.” The second part (part 2) related to the transcribed interview texts from the two rounds of interviews and linked to “the home phase” (Saldaña 2003). In order to identify how themes developed over time, the parts were considered both as separate parts and as a whole.

The structural analysis was conducted in two steps. In the first step, a structural analysis of part 1 was performed, leading to derivation of themes related to the hospital phase. The second step comprised a new structural analysis of part 2, in which patterns and themes identified in part 1 were compared to what emerged in part 2. If the patterns or themes from part 1 still emerged, the further process focused on whether and how the patterns or themes changed over time. Part 2 was also explored for new themes. In the process of internal validation of the themes, the two parts of the text were considered as a combined whole.

The structural analysis was completed by creating new texts, which was supported by tables illustrating the dialectical movement between units of meanings and the units of significance, and themes related to the time point in the transitional period after an AECOPD (Pedersen 1999).

On the third level, the parts derived from the structural analysis were assembled and put back into a narrative communication (Ricoeur 1976). Accordingly, the identified themes were put into dialogue with the researcher’s pre-conceptions, relevant nursing literature and other research results (Pedersen 1999). In the light of that, the results of the structural analysis underwent a further interpretation.

In addition to this, the implications of the study for future practice, training and research were discussed. In that way, the results of the study raised above the actual time, place and persons related to the concrete experiences gained from the patients and their family members, and hence, the results of the study moved from the specific to the general (Bruun 2010). Because a text, according to Ricoeur (1976), always allows for more than one interpretation, the results were discussed several times with research fellows in the field.

Through this process, it was possible to reflect in new ways on the significance of participation in healthcare to patients and their family members, and thereby to achieve a new level of comprehensive understanding.

6. Theoretical nursing framework

This section presents the nursing scientific and practical framework constituted by Merry Scheel's interactional nursing practice theory (Scheel et al. 2008). This approach is chosen because it forms the basis of taking a focus on a patient and family member perspective. The presented framework represents a part of the researcher's pre-conceptions, and the underlying thinking will be included in relation to the discussion of the results.

6.1. Nursing as an interactional practice

Merry Scheel (1929-2007) was a leading Danish nursing scientist, who worked to make nursing into a scientific discipline. In her work, Scheel developed a theory that was founded on the thinking of several philosophers and rooted in nursing practice. She can be seen as a pioneer within person-centred nursing, while she was concerned with ethical challenges in every encounter with the patient, and wanted to place the patient more in focus than had other theorists at that time (Hall 2015).

Scheel's message was that nursing as an ethical practice should create the conditions for patients to look after themselves better in relation to health and illness. To be able to create such conditions, the dialogue and interaction with the patients, their relatives and other healthcare professionals is essential (Scheel et al. 2008).

One of the underlying assumptions of interactional nursing practice theory is expressed in Scheel's view of the human being. The human being is seen as an active and acting being. Because of the body, the faculties and the feelings, the human being is enabled to give form to the biological given, and so to perform free actions in a moral and reasonable way (Scheel 2005). The human being is responsible to her/himself and society, and is always in social relationships with others. This process is not static, but ongoing and lifelong. In interactional nursing practice, nursing is seen as a mutual caring activity, where the nurse and the patient engage in joint activities and where the nurse is concerned with helping the patient and the relative to see opportunities in the situation and thereby to encourage free actions (Scheel et al. 2008).

Scheel argues that interactional nursing practice is in the area of tension between the natural, the human and social sciences. She is inspired by the German philosopher Habermas' thinking around three types of reasons and three corresponding modes of actions (Scheel et al. 2008). Through the modes of action, the three science fields – the natural, human and social sciences – have been operationalised into practice:

The cognitive-instrumental mode of action relates to the natural sciences and it is active, engaging, and focused. It tends to be problem solving and result oriented and is aimed at efficiency. It is a nursing activity that is concerned with the patient's bodily needs and instrumental and technical activities, such as the COPD patient's need of help to manage complicated inhaler techniques and medication, and to adapt to healthy lifestyles (Scheel et al. 2008).

The aesthetic-expressive mode of action is linked to the human sciences. This mode deals with the nurse's self-knowledge, self-reflection and understanding of the patient and his/her situation and the surrounding environment. This activity is not result oriented but aimed at a mutual dialogue to which all parties can relate reflectively, as well as relating to cultural values (Scheel et al. 2008). With regard to this study, the dialogue could be concerned with the COPD patient's capability to self-manage and the family member's concerns about actual and future care.

The moral-practical mode of action corresponds to the social sciences and is concerned with nursing activities related to the dialogue and collaboration with the patient in accordance with ethical norms. In the relationship between the nurse and the patient, the all-important issue is what his/her situation demands of the nurse (Scheel et al. 2008). The nurse's efforts to engage patient and family participation in healthcare appropriately are included in this mode of action.

All three modes of action are integral to every nursing situation, but the nurse must at any time make a qualified judgement of the current situation to ascertain which mode is the most appropriate (Scheel et al. 2008). The dominant mode of action will depend on the nature of the situation, the specific problems and the context in which the nursing is done. Any qualified judgement has to be founded on an insight into the patient's life situation. This implies recognition of the other as a person, and if this is not the case, caring can degenerate into becoming authoritarian, a violation or oppression of the patient (Scheel et al. 2008).

According to Scheel (2005), interactional nursing practice theory points to the nurse's moral obligation to provide care for the patient and the relative when needed. Caring must be adapted to the individual situation and implies multi-faceted activities, such as, for example, encouragement to self-care, which relates to the clinical practice on which this study is based. Scheel (2005) put forward that self-care and care cannot be seen independently of one another. Self-care is essential to strengthening the patient's ability to exercise self-help, but she warns against making self-care into a superordinate and governing concept, and translating it into practice without care. In practice, nurses must be able both to practise care and to support to self-care (Scheel et al. 2008). Qualified judgements must be made in each situation, to find out when to practise either care or self-care, or both.

Thus, in order to achieve qualified nursing, it is pivotal to base the judgement on both reason and emotion and to ensure that care is provided in a way in which patients and their relatives can acquire liberating action competence (Scheel et al. 2008). Besides, it is characteristic that qualified nursing also builds on cooperation between nurses and interdisciplinary cooperation, and that it is important in order to preserve and extend individuals' opportunities for health and wellbeing in relation to specific persons, communities and situations (Scheel et al. 2008).

The part of the empirical investigation that involves participant observations and interviews related to encounters with healthcare professionals in the clinical setting is not limited to the involvement of nurses. However, because of its theoretical foundation, the understanding associated with interactional nursing practice is found to be appropriate to draw on in the discussion related to any interactional healthcare practices.

The application of Scheel's (2005) practice-oriented interactional nursing theory to this study provides a framework to reflect and translate the obtained knowledge into a person-centred caring practice. Moreover, the Ricoeur-inspired approach to the research can be considered to provide an appropriate platform to achieve knowledge, which might be of great value for an interactional practice that is responsive of the meaning of the lived experiences of COPD patients and their family members.

6.2. Other theoretical perspectives

In addition, the discussion of the results in the papers draws on elements of other theories, i.e. Alaf Meleis' theory of transition (Meleis et al. 2000), Hans Georg Gadamer's philosophy on understanding as a fusion of horizons (Gadamer 2004), and Charlotte Delmar and colleagues' philosophy on achieving harmony with oneself in life with chronic illness (Delmar et al. 2005). These theoretical perspectives are further presented in the papers.

7. Ethical considerations

The study was approved by the Danish Data Protection Agency (see Appendix D). In accordance with Danish law, the study was not notifiable to the Regional Committee on the Health Research Ethics. The study was carried out in accordance with the Danish Code of Conduct for Research Integrity (Ministry of Higher Education and Science 2014). This meant that honesty, transparency, and accountability should pervade all phases of the research process. In line with the researcher's responsibility in the Code of Conduct (Ministry of Higher Education and Science 2014), the researcher properly retained, stored and managed field notes and interview transcripts confidentially and in a way that allowed the results to be assessed and the procedures to be retraced.

Publication and communication of research is another area addressed in the Code of Conduct (Ministry of Higher Education and Science 2014). To deal properly with the responsibility of researchers to publish and communicate their research, the results of this study are presented in anonymous form in the three papers that form part of this thesis. In this work, adequate references to others' work are ensured and the contributions of the co-authors are carefully presented.

In accordance with applicable ethical rules, all the participants in the study received written and oral information on inclusion at the hospital (see Appendix A). They were informed that participation was voluntary, were guaranteed anonymity and ensured confidentiality. All participants were given time – at least one day – before informed consent was to be provided (see Appendix B).

During the process of inclusion and participant observation during hospitalization, precautions were made not to incur additional harm to vulnerable COPD patients and family members (World Medical Association 2013). For example, patients whose conditions worsened or who needed treatment with non-invasive ventilation, were not approached before they were once again stabilized.

Furthermore, at every new contact with the participants, oral information about the purpose of the study, and thus the presence of the researcher, was repeated to ensure that they understood that it was possible to withdraw from the study without adverse implications for their care. Initially, the participants were informed that, besides being a researcher, the researcher was also a nurse. This fact could affect the interaction during the participant observation and interviews. Therefore, provision was made for the participants to seek for advice regarding, for example, their symptoms, treatment, and opportunities for follow-up interventions. For instance, they could be encouraged to talk to a nurse on the ward or at the outpatient clinic. During the researcher's contact with the participants, both at hospital and at home, their comfort and well-being was in focus. Sometimes, this could require adaptation to circumstances, such as increased shortness of breath and fatigue.

One of the interviews with a relative happened to be a bereavement interview. This was conducted because the relationship between the researcher and family member had already been built up during the previous hospitalization. Additionally, the fact that the participant was in close contact with her general practitioner established a backup, given that professional help was needed after sharing emotions and reflections with the researcher.

In the repeated contacts with the participants, it was the experience that the participants developed great trust in the researcher and therefore showed great willingness to talk about sensitive issues. In the interviews at home, it was therefore particularly emphasized that the participants understood the purpose of the interview and that they had the name of an appropriate healthcare professional to contact, if needed.

In the contacts with the patients and family members, which sometimes were individual and sometimes joint, care was taken to preserve confidentiality. This is important, when, as in this study, people are met more than once and the interviews build on information from the previous meetings. For example, in research where patients were interviewed alone before carers were interviewed alone, the carers could show curiosity or concern about what has been said previously by the patient about the carer (Kendall et al. 2009).

Furthermore, the final two interview rounds took place primarily in the participants' homes, and therefore it was found most appropriate to let them decide whether they wanted to be interviewed together or separately. Other researchers have likewise argued that ethical concerns must be given a higher priority than methodological issues, when interviewing married couples (Norlyk et al. 2016). In summary, repeated considerations were made throughout the period of data collection to ensure that the participant observations and interviews were conducted in a way that inconvenienced the participants as little as possible.

8. Results

As clarified in the previous chapter, the results of the study are based on qualitative methods, which were carefully chosen to answer the research questions (Carter & Little 2007). The results represent two perspectives, namely the patients' and their family members', and cover a course of different situations and settings in both the contexts of the hospital phase and the home phase of the transitional 18-month study period.

The results are presented in three papers (see Chapter 16). Each of the papers represents either one or both of the perspectives, and focuses on one or two of the context-bound phases.

In paper 1, one perspective is presented; namely, the patients' experiences are presented in relation to the hospital-phase and the subsequent home phase.

In paper 2, two perspectives are presented; namely, the patients' and their family members' experiences regarding the hospital-phase and the subsequent home phase.

In paper 3, two perspectives are presented; namely, the patients' and their family members' experiences in relation to the home phase only.

In order to provide an initial overview, firstly the naïve reading of the entire study is presented in the following section. Next, in order to give an overall review of the results, the structural analysis is illustrated in the tables below by means of excerpts from the structural analysis as they are presented in each paper (Papers 1-3). This complements the papers, which by their presentation of the results related to different combinations of perspectives and phases; each of them represents separate parts of the larger study. Finally, in order to prepare the further critical interpretation and discussion, key areas in the results across the three papers are presented in the last part of the results section.

8.1. The naïve reading

The naïve reading of the entire text material opened up areas of significance in patients' and their family members' experiences in relation to the lived life with COPD in the transitional period during and after hospitalization for a severe AECOPD. The overall impression was that patients and family members over time had various concerns and considerations about whether and how to be ready manage and capable of managing their care situation. Before discharge, experiences related to participation in healthcare seemed to be associated with preparations for going home, while the experiences at home could link to a struggle to deal with the daily self-management. Over time, the daily struggle seemed to affect family life. Furthermore, the accessibility and the interaction with healthcare professionals could be related to both positive and negative experiences.

8.2. The structural analysis

Through the structural analysis and interpretation, the meaning of participation in healthcare to COPD patients and their family members over time became clearer. The results of the study are outlined in schematic tables below (Table 7-9), by showing how themes were derived from the selected quotations from the entire text material. In the tables, the process of analysis is demonstrated from the units of meaning, in terms of "what is said," to the units of significance, in terms of "what is spoken about," to the emergence of themes.

8.3. Paper 1

In Table 7, the results from the first paper (Paper 1) are presented as they appeared in the structural analysis. The aim of the paper was to explore COPD patients' experiences of participating in their care in the transitional period around discharge from hospital and in their own subsequent day-to-day care at home following a severe AECOPD. The table is divided so that the first part shows field notes (FN) from the participant observations in the hospital context and the second part shows quotations from the interview rounds (IW) at home. P refers to patients and the number refers to the number allocated to the participant in the study.

Table 7. Examples of the systematic process in the structural analysis in relation to Paper 1

Units of meaning What is said	Units of significance What is spoken about	Main themes and subthemes
Hospital phase:		Struggling to regain a sense of control
<i>The patient says to the nurse: "I don't want to go home yet... I'm too tired ...I'll only fall back into my old ways" (FN, P12)</i>	Unprepared and seeking to prolong the stay at hospital	Building up strength and readiness for discharge
<i>Patient: "I would like to know if my COPD has got worse." Doctor: "Yes, that's the nature of the illness ..." The patient later relates that she is happy with the doctor's explanation (FN, P13)</i>	Informed appropriately to be able to relate to own situation	Seeking clarity and confidence
Home phase:		Striving to comply with received advice and encouragement to maintain well-being
<i>Patient: "The doctor said that it was COPD and that I should learn to live with it ... I was a bit angry ... despondent ... now I can't do this and I can't do that" (IW P15, 11 months after discharge)</i>	Discouraged and seeking to renegotiate the meaning of living	Struggling to stay motivated and confident
<i>Patient: "The doctors say that I should go to the doctor in good time, but I try to put it off ... it's stupid, I can see that myself" (IW P9, 6 months after discharge)</i>	Advised to seek help in good time, but reluctant	Asking for help

8.4. Paper 2

In Table 8, the results from the second paper (Paper 2) are presented as they appeared in the structural analysis. The aim of the paper was to explore COPD patients' and their family members' experiences of both participation in care during hospitalization for an AECOPD, and of the subsequent day-to-day care at home. The table is divided so that the first part shows field notes (FN) from the participant observations in the hospital context and the second part shows quotations from the interview rounds (IW) at home. P refers to patients, F refers to family member and the number refers to the participant number in the study.

Quotations from interviews and field notes represent both the patients' and the family members' perspectives. They are presented separately and, in order to clarify the interrelationship, perspectives are placed opposite each other.

Table 8. Examples of the systematic process in the structural analysis in relation to Paper 2

Units of meaning What is said	Units of significance What is spoken about	Themes
Hospital phase:		
<u>Patients' statements:</u> <i>"They probably deal with me well, I hope to go home soon, but I don't know...my daughter will talk to the doctor" (P11, FN)</i>	Losing the overview and be challenged in speaking for oneself	Balancing between powerlessness and influence
<u>Family members' statements:</u> <i>"I sort of keep a bit of an eye on what they [the healthcare professionals] give him [her husband]" (F4, FN)</i>	Showing worries and hyper-vigilance in relation to treatment	
Home phase:		
<u>Patients' statements:</u> <i>"I have to take action ... she [his wife] prods me to do so ... she has to" (P9, IW 6 months after discharge)</i>	Feeling positively protected	Navigating between mutual pressure and consideration
<u>Family members' statements:</u> <i>"He [her husband] sits on the sofa for too long ... I have to get out every morning, because, otherwise, I'd go mad. Sometimes he has to be forced a bit" (F14, IW 5 months after discharge)</i>	Being annoyed by needing to watch and to encourage	

8.5. Paper 3

In Table 9, the results from the third paper (Paper 3) are presented as they appeared in the structural analysis. The aim of the paper was to explore COPD patients' and their family members' experiences of interacting with healthcare providers over time after a hospitalization for a severe AECOPD. The table shows quotations from the interview rounds (IW) at home. P refers to patients, F refers to family members and the number refers to the participant number in the study.

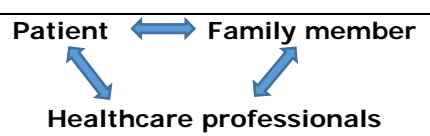
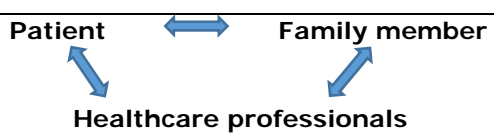
Table 9. Examples of the systematic process in the structural analysis in relation to Paper 3

Main theme: Between hope and hopelessness		
Units of meaning What is said	Units of significance What is spoken about	Subthemes
<i>Patient: "It [the rehabilitation programme] has got me going ... I have vacuum cleaned several times and go out with others ... everything looks, maybe, a bit brighter now" (P13, 13 months after discharge)</i>	Empowered to develop hope	Dealing with empowering healthcare services
<i>Patient: "It's hard, when my GP says that he won't treat my insomnia while I'm attending the lung clinic, and they [the health professionals] there say that I should go to my GP" (P5, 10 months after discharge)</i>	Stuck with opposing advice - and left without help	Navigating between healthcare providers
<i>Relative: " It should preferably be our usual home helper who comes and helps my husband with his care in the mornings. Otherwise he has to talk more and be more engaged, and then it affects his breathing" (F4, 9 months after inclusion)</i>	Stressed about changes in usual healthcare provision	Collaborating with healthcare providers at home

Presentation of results

Based on the three papers, the results are synthesized in four key areas, each of which concerns important aspects of what matters to patients and family members in order to participate actively in healthcare during the transitional period after the AECOPD. In the following, the presentation of the results is structured around the four key areas: Dealing with one's own care before discharge; dealing with one's own day-to-day care at home; balancing self-management and family life; and seeking the balance in the relationship with healthcare professionals. In Figure 3, the results are represented as an illustration of the transition between the hospital phase and the home phase, the interaction between the COPD patient and the family member, and the interaction between patients, family members and healthcare professionals.

Figure 3. Schematic presentation of the results of the study

Participation in healthcare between power and powerlessness from the COPD patients' and their family members' perspective		
Hospital phase	↔	Home phase
Dealing with one's own care before discharge Concerns, considerations and efforts related to decisions and activities before discharge	↔	Dealing with day-to-day care at home Concerns, considerations and efforts related to decisions and activities during recovery and continued daily living
COPD patient Overwhelmed, uncertainty, mentally and practically preparing to go home, struggling to regain a sense of control, building up strength, seeking information and clarity, competence and confidence, seeking support from family members, seeking influence, readiness to take over responsibility for one's own care	↔	COPD patient From shaken to normalized, dealing with ups and downs, discouraged or encouraged after stay at hospital, self-managing, seeking to balance healthcare professionals' advice and encouragement with everyday life, striving to stay motivated and confident, need of help from others, balancing between wanting to manage on one's own and deciding when to ask for help
Patient ↔ Family member Stress, family members' concerns and vigilance, family members' contribution to being seen, heard, and understood, feeling seen as a resource, speaking about the patient's and the family's case	↔	Patient ↔ Family member Affected family life, dealing with annoyance, frustration and bad conscience, commitment and closeness, navigating between mutual pressure and consideration, family members' support and demands, protection and patients' feelings of overprotection, family members' unmet needs for support
Patient ↔ Family member  Healthcare professionals Challenged in understanding messages and instructions, challenged or enabled in being received, engaged and recognized, activated, seeking influence and negotiation about treatment, time for discharge and follow-up	↔	Patient ↔ Family member  Healthcare professionals Being followed up or lost in transition, access and interaction with services, alliances, engaged or less engaged, activity and passivity, between hope and hopelessness, encouraged and empowered to improve capacity to deal with day-to-day care

Dealing with one's own care before discharge

For the patients in the study, this was not their first hospitalization for the severe AECOPD, but one of several. Although the acute episode and the admission was looked at as something frightening and troubling, it was described as something that was to be expected in having COPD. Having learned from previous episodes, admissions, and possible readmissions, getting ready for discharge was strongly emphasized by both patients and family members (Papers 1 & 2). Therefore, after having overcome the acute phase, participating in activities and decisions about care was mainly directed at being mentally and practically ready to self-manage at home again (Papers 1 & 2).

Through their preparations, the patients struggled with uncertainty and tried to regain a sense of control. To the extent that they could manage, they put effort into building up strength, and into acquiring sufficient clarity and confidence in their own capabilities to look after themselves again (Papers 1 & 2).

However, the demands associated with imminent discharge before full recovery could be so dominant that experiences of increased breathlessness, anxiety, and powerlessness could occur and make participation in one's own care overwhelming. As a response, patients tended towards handing over the management of their situation to others and, when possible, and when wanted, they sought help from their family members to be seen, heard, and understood properly. If family members were involved, they played a central role in seeking influence on decisions about such issues as the course of discharge (Paper 2). Although the hospitalization made them feel stressed, they showed a readiness to participate, but this could be accompanied by worries and hyper-vigilance in relation to the received care of their relatives (Paper 2).

In their efforts to contribute positively, feeling recognized by the healthcare professionals as a resource was of great importance. Feeling seen in that way could allow family members to speak their case, and thereby to contribute to better clarity, confidence, and agreements about the planning of the discharge (Paper 2). Through the overall joint efforts, patients and their family members sought to deal with powerlessness and to achieve power enough to take over responsibility for the day-to-day care at home again (Papers 1 & 2). Thus, it became clear that participation related to healthcare meant seeking to feel ready and to balance between feelings of power and powerlessness.

Dealing with one's own day-to-day care at home

In the transitional period under investigation, day-to-day care at home implied dealing with the effects of continuous minor or major changes in health and illness, which were related to feelings of ups and downs. These shifts in levels of breathlessness and other symptoms of COPD and its comorbidities meant that the illness experience could vary from time to time, and from day to day, and be associated with a demand to strike a balance between perceptions of an acceptable level of power and sometimes having harder feelings of powerlessness (Papers 1-3). Among the patients in this study, recovery turned out very differently, but for all of them, their daily balance was disrupted for a time before being normalized again. After returning home, experiences of success in having participated in training activities and decisions in relation to the course of the discharge were associated with a good transition experience, and of a growing power to self-manage again.

Feeling well prepared for recovery in this way gave courage and confidence in how to handle future exacerbations, how to deal with new treatments, and how to get appropriate help and support (Papers 1 & 2). On the contrary, feeling abandoned and back on their own could be a stressful experience, which could leave patients and their family members discouraged and with long-term perceptions of powerlessness (Papers 1 & 2).

In their sustained efforts to maintain their health and well-being, the patients strived to balance received advice and encouragement from healthcare professionals with their everyday lives (Papers 1 & 2). Over time, however, dealing with the many illness-related troubles could imply a struggle to stay motivated and confident in own capacity to self-manage.

Experiences of limited power could affect patients' development of reactive strategies for their self-management, which, on the one side could be favourable in making daily life manageable, and on the other could be a hindrance to preventive activities, and to planning ahead (Paper 1). Doubt and concerns in relation to the shifting demands to day-to-day care implied that the need for help and support could vary, but was persistent. The need for help appeared to be difficult to handle and involved a balancing act between deciding when to ask for help and wanting to manage on one's own (Papers 1-3). The management of ongoing episodes of acute breathlessness and the accompanying feelings of anxiety could include long-term considerations and frustrations for both patients and family members. Although they were encouraged to seek help in good time, a desire to wait and see could be preferred, and may be relevant, but such reluctance could imply a risk of delayed help (Papers 1 & 2). Experiencing the access to appropriate help as difficult or having experiences of poor encounters with healthcare professionals could present further barriers to seeking help (Paper 3). Hence, when dealing with their own care at home, it became evident that participation related to healthcare meant seeking to balance between feelings of power and powerlessness in a struggle to stay confident, motivated, and to ask for help.

Balancing self-management and family life

For the patient, being able to get ongoing support and help from close family members played a significant role in how they managed to deal with their own care before discharge and in the day-to-day care at home (Papers 2 & 3). For the family members, participating in their relative's self-management was linked to commitment and satisfaction, but certain concerns and difficulties could also turn it into a burden. A key issue, which made them feel lonely, was that, over time, they suffered from a lack of opportunity to discuss their own particular concerns with healthcare professionals (Paper 2).

Over time, the struggle of dealing with day-to-day care could develop in a way that affected family life and became a source of tension between the parties. In order to protect the closeness and avoid conflicts, patients and their family members sought to navigate between mutual pressure and consideration (Paper 2). For the family members, concerns and fear for their relative's well-being could make them vigilant and lead them to demand that the patients adhere better to medication and healthy lifestyles. Family members tried to be considerate before they intervened, but patients could respond to pressure from family members with annoyance. Although they knew their family members' interventions were well intended, negative experiences of overprotection and increased dependence could be difficult to cope with. The patients wanted to be considerate and do their best to fulfil the demands made of them, but they also wanted to do things on their own. On the other side, family members reported having a bad conscience if they became impatient and put too much pressure on their ill relative. Accordingly, the significance that patients and family members attributed to their own concerns and mutual consideration pointed to the importance of a balanced family life to be able to self-manage appropriately in ways that were in accordance with their personal needs and their joint needs (Paper 2).

In addition, differing views between them on the illness and their life situation seemed to be of significance to how patients and family members approached day-to-day care. Worries about the future, and a tendency shown by patients to take one day at a time could be challenging for family members. When they sought to take a more pro-active approach to the patient's efforts, and if this became a cause of disagreement, a feeling of being left alone to cope with loneliness and frustration could be the consequence (Papers 1 & 2).

That is, the patient and family members affected each other, and when one person in the family was affected by COPD, family life became affected. The shifting experiences of power and powerlessness was of significance to how participation in healthcare at hospital and day-to-day care at home was dealt with, and how a balanced family life over time was maintained.

Seeking a balance in the relationship with healthcare professionals

Follow-up after discharge, which led to experiences of easy access, appropriate interaction and well-established alliances with healthcare professionals, was pivotal for both patients and family members to remain active participants in healthcare in the clinical setting and in the subsequent day-to-day care at home (Papers 1-3). Throughout the study, they tried to take and valued taking an active role, but certain issues related to the manifestation of illness, the situational context, personal resources, and whether they were seen, heard and understood in the encounters with healthcare professionals, appeared to make their work complicated and the accompanying responsibility difficult to deal with (Papers 1-3).

In the encounter with the healthcare professionals, being met with clear communication in a mutual dialogue was experienced as conducive to feeling engaged to participate more actively in their own care. To be seen, heard, and understood in a proper way was an important part of that and important to the experience of motivation, confidence, and competence (Paper 2). In the interactions with healthcare providers, receiving information and instructions was appreciated but it was not always easy to understand what was given, nor to ask further about it. Furthermore, when healthcare professionals were not sufficiently sensitive to, or did not take the expected responsibility for presented problems, frustrations, and concerns, the foundation for mutual collaboration and negotiation was challenged (Paper 1-3). Being less engaged affected self-management, which could become limited and led to frustrations and doubts about whether it would be possible to turn things to the better; these feelings could persist for a long time (Papers 1-3).

Accordingly, the healthcare providers' approach, and also the way that healthcare was received, played a central role for patients and their family members in how they sustained their hope and confidence (Paper 3). To receive praise, proper encouragement and meaningful help and support to see opportunities and set goals for the future were ways that enabled feelings such as becoming proud, engaged, and empowered, and that therefore facilitated activity and the maintenance of hope (Papers 1-3). On the contrary, experiences of difficulties in navigating different healthcare services and of being lost in transition between hospital and home could be associated with the development of passivity, doubt and hopelessness (Paper 3). For patients and their family members, facing such shifts between hope and hopelessness could be followed by increased troubles in relation to their daily self-management. Over time, it seemed that the availability of healthcare services and the interaction between patients, family members, and healthcare professionals was of importance to feel encouraged to participate in healthcare and thereby to maintain or increase feelings of hope and power to be able to improve one's health and well-being.

9. Discussion

The thesis is based on a study that explored the meaning of lived experiences related to COPD patients' and their family members' participation in healthcare following a severe AECOPD as it occurs over time and on several occasions. Because of the longitudinal design, the results represent experiences over a coherent pathway that traverses settings and covers a long-term period after a severe AECOPD. A study that follows COPD patients and their family members from hospital to home contributes to the still limited, but requested, research that would give broader and deeper knowledge of the experience of chronic illness than what can be obtained by studies concerned with people's positions at a particular point in time (Kralik & van Loon 2009). Other longitudinal qualitative studies have already investigated the experience of living with COPD from both a patient and a family perspective. Yet, they largely focus on advanced care needs and end-of-life issues (Clancy et al. 2009, Ek & Ternestedt 2008, Ek et al. 2011a, Ek et al. 2011b, Kendall et al. 2015, Landers et al. 2015, Marx et al. 2016, Pinnock et al. 2011); or on transitions during the rehabilitation period, solely from the patient's perspective (Halding et al. 2010, Halding et al. 2011, Halding & Heggdal 2012). By virtue of its focus on patient and family participation in healthcare, this study supplements these longitudinal studies with important knowledge about both patients' and their family members' differing and changing experiences of their own work in daily self-management with COPD over time.

In the following section, the main results from the underlying papers that constitute the thesis are discussed in relation to existing research literature and nursing theory. Delmar's and Meleis' theories are applied in order to elaborate further on patients' and family members' readiness, ability and opportunity to play a central role in the management of the illness (Delmar et al. 2005, Meleis et al. 2000). Scheel's theory of interactional nursing practice is drawn upon to discuss results related to the interaction between patients, family members and healthcare professionals (Scheel et al. 2008).

In order to expand the discussion on each paper, the following discussion spans the results from all three papers. The discussion is structured in five parts under the following headings: Preparation for discharge; The struggle to self-manage and ask for help; The relationship and dynamics among patients and family members; The interaction between patient, family members and healthcare professionals; Reflections on patient and family-centred care within the area of COPD. The results of this study are referred to by the following references: Paper 1, Paper 2 and Paper 3.

Then, the methodological considerations of the study are treated in a discussion. Finally, the results are discussed in relation to implications for future clinical practice, education, and research.

9.1. Preparation for discharge

The study showed that, for both patients and family members, participation related to healthcare before discharge entailed striving to feel ready to take over the responsibility for the further day-to-day care at home (Papers 1 & 2). This confirms the results of a previous study about patients' with severe COPD and their family members' preparations for discharge, which indicated that COPD patients' weakness could lead family members to seek knowledge of the situation and influence discharge planning. However, this was not without challenges and

frustrations (Andersen et al. 2014). In a similar way, other studies have pointed to how lack of involvement from healthcare professionals could make readiness for discharge difficult for patients with respiratory disease and their family members. Not feeling properly informed and involved in discharge planning could complicate recovery and make the return home uncertain (Bailey 2004, Clarke et al. 2010). The significance of such challenges in the transition from hospital to home can be understood further in the light of the nursing theory of transition (Meleis et al. 2000, Schumacher & Meleis 1994). According to the theory, a transition involves people's responses during a passage of change, such as when illness occurs or worsens (Meleis et al. 2000). The way that the patients and family members in the current study showed uncertainty and powerlessness corresponds to the vulnerability that Meleis and her colleagues link to the experience of health-illness transitions. They point to the complexity in transitions, in which people often go through more than one kind of transition concurrently (Meleis et al. 2000). Therefore, undergoing a transitional period of recovery and a shift in the setting from hospital to home can be a transitional process, which might be complicated, if one is not enabled to participate properly in one's own care.

However, although it was demanding, the hospitalized patients tried to deal with encouragement from those in their surroundings, and in becoming gradually more active and ready for discharge. Motives for not being ready could vary, but what seems to be the most frightening motive was whether they would be able to handle new severe episodes of breathlessness on their own. Having an AECOPD was described in ways that could be associated with a loss of control that provoked uncertainty and anxiety until it again was under control (Papers 1 & 2). Anxiety experienced in relation to COPD is a well-documented phenomenon (Bailey et al. 2016, Disler et al. 2014, Willgoss et al. 2012). The relationship between anxiety and breathlessness for patients with advanced COPD has been described as the dyspnoea-anxiety-dyspnoea cycle, which indicates how the two can affect each other in a way that makes anxiety escalate (Bailey 2004). In the light of this, the significance of feeling ready to deal with such situations at home is understandable. Willgoss et al. (2012) address self-management in the form of learning self-control and planning to avoid triggers, as an important way for patients to take control over breathlessness and panic attacks. Thus, becoming confident in how to self-manage and avoid anxiety, including how to get the help needed seems to form the focal point for patients to prepare for discharge.

During the hospital phase of the transitional period, asking about plans and treatment, and trying to negotiate time for discharge were strategies used during preparation, which were used to buy some time for more rest and training (Papers 1 & 2). In order to deal well with these efforts, support from healthcare professionals was important. Feeling recognized while participating in preparatory activities was important in order to feel valued and encouraged to go home. Nevertheless, lack of the required power to participate in the preparations could make patients draw upon help from their family members. For family members, participation was perceived in positive ways, but experiences of not being seen by healthcare professionals as a resource, could make their active involvement demanding and stressful (Paper 2). Similarly, Bove et al. (2016) found that spouses of patients with COPD preferred to be involved, but that difficult access, not being considered as an expert, and being abandoned by healthcare professionals could make them feel powerless. According to Meleis et al. (2000), proper preparation and knowledge are facilitating conditions for the development of confidence and coping, which can be conducive to achieving healthy transitions (Meleis et al. 2000). The significance of limited support for participation in healthcare before discharge might then challenge achievement of a healthy transition.

The study pointed, in addition, to the importance of achieving a sense of control and to finding a balance between powerlessness and influence before discharge (Paper 1 & 2).

In the light of Meleis et al.'s (2000) Transition Theory, being sufficiently informed and confident is critical to good preparation to be able to cope with transition. Furthermore, if coping is seen in an existential way, as proposed by Delmar et al. (2005), coping with a chronic illness is about controlling one's life in a way that can be understood as achieving harmony with oneself. In the same way, Meleis et al. (2000) argue that, in transitions, there is always a subjective element of achieving a sense of balance in one's life. Hence, participating actively in the preparations for the transition from hospital to home following a severe AECOPD means getting ready to take over the responsibility for the subsequent day-to-day care at home in ways that enables a sense of balance in life.

9.2. The struggle to self-manage and ask for help

The study revealed that, when dealing with one's own care at home, participation related to healthcare meant seeking to balance, over time, the changing demands involved in self-management of the many illness-related troubles with everyday life. Although the patient participants differed in how the recovery from the AECOPD progressed, their feelings of control were shaken for a while (Papers 1-3). In the light of Delmar et al.'s (2005) research into the area of living and coping with chronic illness, a life with chronic illness is a life with ongoing shifts between feelings of loss of control for a time and feelings of self-control. This takes place in a pendular movement towards acceptance of the situation. Through this process, hard feelings such as uncertainty, anxiety, and powerlessness can occur (Delmar et al. 2005). That is, managing the day-to-day care of the COPD means going through an emotional course of ups and downs, and the resulting fight for control can be seen as a constant movement towards coming into balance with oneself.

During the home phase of the transitional period, complying with advice and encouragement was experienced as important to maintaining wellbeing; however, over time, staying motivated and confident in one's own capacity could be a challenge (Paper 1). In everyday life, dilemmas, concerns and hopelessness related to loneliness and powerlessness were mentioned as demotivating for proper self-management, such as, for example, maintenance of healthy lifestyles. When this was the case, perception of illness could be of significance to how self-management was approached (Paper 1). This result confirms the significance of a belief in, a positive or a negative outcome as to how confident patients are in their capacity to self-manage. Furthermore, other studies have pointed to a negative impact of social isolation and social stigma on self-management (Disler et al. 2012).

Halding et al. (2010) found that experiences of self-blame and stigmatization related to smoking were seen as a key cause of social isolation in COPD patients, who had attended a pulmonary rehabilitation programme. Consequently, the self-inflicted aspect of the illness could make patients feel guilt, shame, and less worthy of treatments, which might improve self-management (Disler et al. 2016, Halding et al. 2011). The problematic of stigmatization was not expressed explicitly in the present study; yet, patients who started smoking again after a period of cessation showed social isolation and a depressed mode, but also pleasure related to smoking, as motives for conducting unhealthy self-management (Paper 1). Thus, illness perception, dilemmas and emotions can play a pivotal role in the manner in which patients make sense of their situation and approach their day-to-day care.

It is also shown that dealing with an ongoing need for help and support appeared as a balancing act between asking for help and managing on one's own (Papers 1 & 2).

Returning to Delmar and colleagues, seeking help can imply a balance between feeling dependent on help from others and a desire to feel independent of help from others, which could be difficult to deal with (Delmar et al. 2006). The difficulty in this balance appeared in this study in a reluctance to seek help during episodes of AECOPD, which could include considerations about how to judge the situation and a desire to wait and see whether things gradually turned out for the better. This meant that, despite being encouraged to seek help in time, help was not sought until they felt unable to manage the situation any longer. Such an attitude could be seen as appropriate self-management, but could also involve a risk of delayed help (Papers 1-3). Other studies have pointed to the same difficulties in COPD patients' reluctance to seek help. Similar to our study, Korpershoek et al. (2016) suggested that recognition of exacerbations and, consequently, taking adequate self-management action, such as seeking help, could present challenges among patients with COPD in a minor to severe degree. Williams et al. (2014) highlighted that patients with moderate to very severe COPD could teach themselves to identify exacerbations by assessing both visible symptoms based on clinical parameters and invisible symptoms based on experiential knowledge. This made them experts in their own self-management, although seeking help on time still could be a challenge (Williams et al. 2014).

Additionally, the current study revealed that difficult access and previous experiences of non-supportive encounters with healthcare professionals could be a barrier to seeking help (Papers 1-3). This is consistent with Korpershoek et al. (2016), who showed that having trust in healthcare professionals was important to how patients approached these challenges. From the accounts of the participants in the present study, a perception of loneliness and resignation related to not being able to change the situation could challenge patients in seeking help for daily troubles between exacerbations (Papers 1-3). Harrison et al. (2015) shed further light on such social influences of self-management, including active help-seeking. After a hospitalization for an AECOPD, they found that shame and stigmatization could reflect challenges for patients as to their self-worth and be associated with reduced help-seeking and increased isolation (Harrison et al. 2015). Hence, the part of the day-to-day care that is concerned with active help-seeking can be associated with a complexity of influences – and challenge the desire to be as independent as possible.

9.3. The relationship and dynamics among patients and family members

The study demonstrated that the struggle with daily self-management could affect the relationship between patients and family members and, thereby, challenged the balance in family life (Paper 2). Through the transitional period in focus for this study, it appeared that an AECOPD and frequently changing demands on one's own care could be related to an increased uncertainty and frustrations that affected both parties (Papers 2-3). This is in accordance with an extensive review within the area, which identified that informal carers' challenges often echo patients' challenges, and include many of the same emotional responses (Giacomini et al. 2012). Thus, it seems that the emotional impact of dealing with the effects of COPD might be considerable and contribute to increased strain on family life.

During the home phase, day-to-day care could be a source of tensions and challenge patients and family members in ways that made them navigate between mutual pressure and consideration (Paper 2). From the patients' point of view, their relatives' demands and encouragement about how to relate and act properly in relation to the illness could lead to experiences of dependence and demotivating overprotection (Paper 2).

This result is in accord with another interview study with patients with severe COPD and their family members, in which patients felt overprotected while their family members excessively focused on their illness and were permanently concerned with their health behaviours (Gabriel et al. 2014). This underpins the difficulty in family members' focus on such issues as breathing exercise and physical activity for patients in feeling able to deal with their own day-to-day care in a balanced way. Gabriel et al. (2014) supplement this, by showing that communication in couples could be affected in daily living with COPD, and that patients could find themselves less understood.

This matter was not expressed explicitly in this study, but through the joint interviews with patients and family members, arguments and disagreements in relation to, for example, help-seeking could be interpreted as a sign of such difficult communication and lack of mutual understanding (Paper 2). This indicates that the troubles and frustrations related to day-to-day care could be difficult to talk about and, for patients, could be linked to hard feelings associated with being overprotected and dependent.

From the family members' perspective, concerns and difficulties in being hyper-vigilant, encouraging, and interacting with healthcare professionals could turn the help and support, which they give, into a burden (Paper 2). The significance of family members' difficulties in relation to informal caregiving and navigation in the relationship with their ill relative are well supported by other studies. Bergs (2002) showed that women caring for husbands with severe COPD limited their communication in consideration of their husbands' shortness of breath. In an effort to protect them, the women refrained from confronting their husbands with expressions of strong feelings (Bergs 2002). Another study highlighted that patients with severe COPD did not always reciprocate a desire for more communication, and that this could frustrate family members (Fried et al. 2005). Moreover, Bove et al. (2016) pointed to the development of ambivalence in couples' relationships. This could occur for wives of patients with severe COPD, when they strove to preserve equal dignity and became challenged in how the illness led their partners to be selfish and self-centred (Bove et al. 2016).

A dilemma furthermore became visible in the ways in which family members could present a desire to intervene but, at the same time, tried to be considerate to their relatives' self-determination (Paper 2). In the same way, other research found that partners of patients with severe COPD sought to balance a need to maintain the independence and integrity of both parties and thereby put enormous effort into establishing a sense of continuity in their family life (Aasbo et al. 2016). Differences between patients and family members in illness perceptions, and in how to act, appeared in this study to be a challenge for the mutual relationship. This is in line with findings from a literature review that identified that discrepancy in COPD patients' and their family members' perceptions of the patient's symptoms and health status could be a challenge to informal caregiving (Nakken et al. 2015). An interesting finding in this study revealed that concerns and frustrations could be associated with a preference for patients to be reactive in their approach, while family members could have a need to be more proactive and look ahead (Paper 2). The finding might be understood in their different roles as a patient or a relative. Possibly, the fact that they were not the ill person, and therefore were in a different position, could enable them to be more ready to look forward. As put forward by other researchers, such experiences could be stressful, and, for family members, negative attitudes, such as, for example, resistance in activity or treatment regimes in patients could contribute to a loss of caring motivation and intimacy feelings (Simpson et al. 2010).

This reveals that the way in which COPD patients and family members made sense of the illness and the treatment could differ and affect their relationship. How they managed to communicate and share their mutual understanding was of great importance to how the patient felt supported to self-manage and how the family members felt motivated and managed to contribute thereto.

9.4. The interaction between patients, family members, and healthcare professionals

The study indicated that the availability of healthcare services and the interaction between patients, family members, and healthcare professionals was of significance in feeling encouraged to participate in healthcare and thereby to maintain or increase feelings of hope and power to be able to improve one's health and well-being. Through the transitional period, which was in focus in our study, an ongoing struggle to regain or maintain motivation, skill, confidence in one's own capability, and a balanced relationship within the family indicated a need to have ongoing access to proper medical treatment, and empowering and supporting healthcare services (Papers 1-3).

This struggle draws attention to the difficulties in how to understand the messages from healthcare professionals and in navigating the right services, which could be accompanied by hard feelings of incompetence and discouragement (Paper 1-3). In the previous literature, the challenges in understanding received information, adhering to treatment, making appropriate decisions and accessing support in the community have been described in relation to limited health literacy in patients with COPD (Disler et al. 2012, Roberts et al. 2008). It has been reported, furthermore, that low socioeconomic status and low levels of education are associated with a higher risk of development of COPD (Gershon et al. 2012). Additionally, low socioeconomic status has been found to affect the capacity to self-manage a chronic condition negatively and to isolate patients from receiving the help and support needed (Van Hecke et al. 2017). Clearly, it is critical to take into consideration the significance of economic hardship and low health literacy in training and assisting COPD patients and their family in self-management.

An important aspect of the arrangements around hospital discharge is that patients and family members feel that they are actively participating and ready to look after themselves. In order to meet this, follow-up and rehabilitation interventions can support this process. The official goal is to motivate, engage and coach the patients to positively adapt their health behaviour and develop their skills to manage their illness better (Effing et al. 2016, GOLD 2017). The results of this study highlight both the importance and the challenges for patients of feeling adequately supported to attain such levels of competence and confidence (Papers 1-3).

The significance of the accessibility of, and the relationship and dialogues with healthcare professionals to achieve the required levels of competence and confidence needed to self-manage can be reflected on in the view of Scheel et al.'s (2008) practice theory of interactional nursing. In interactional nursing practice, care activities related to instruction in complicated inhaler techniques and medication, self-management of breathlessness, and energy conservation, can be ascribed to what Scheel et al. (2008) describe as the cognitive-instrumental approach. However, in Scheel et al.'s (2008) thinking, this mode of action cannot exist alone.

In order to address COPD patients' and their families' opportunities, literacy, frustrations, hopes and doubts, when they are in the transitional phase after a severe AECOPD, the aesthetic-expressive mode of action is also important (Papers 1-3). The caring activity related to this mode of action is aimed at establishing a mutual dialogue, whereby all parties can relate reflectively, reach a common understanding, and, based on that, make a decision about the management of the problem.

In the efforts to encourage collaboration with patients and family members, nurses and other healthcare professionals must also include the moral-practical mode of action, which involves care being provided in accordance with ethical norms (Scheel et al. 2008). In this study, the significance of this appeared in the hope that could be facilitated when participation in healthcare was enabled, and in contrast, in the hopelessness that could arise when the healthcare did not match the need for help or was provided in a non-participative way (Paper 3). According to Scheel et al. (2008), the qualified judgement, which the nurse must make in each caring situation, must rely on an ethical reflection upon how and when to intervene without imposing her/his care upon the patient. This is important in order to ensure that the patient is not kept in a weak and undignified position, and that caring does not become a matter of exertion of power over the patient (Scheel et al. 2008). Tobiano et al. (2016a) identified that, for patients admitted to a medical ward, the power imbalance in the relationship with nurses was a barrier to patient participation and that this led to perceptions of patient disempowerment. With reference to interactional nursing practice, the significance of this can be understood in how self-care is closely connected to care. If patients and family members are not helped and supported adequately, they might be left with feelings of guilt and shame related to insufficiency (Scheel 2005). Furthermore, they might not be supported adequately in acquiring the kind of liberating action competence that they might need to be able to improve their capacity for self-management (Scheel et al. 2008). Thus, fruitful and repeated interactions with healthcare professionals in ways that are sensitive to patients' and family members' concerns and considerations regarding their illness and its treatment are crucial in order to deal with the shifting demands to self-management. If this is not the case, the requirement to face greater levels of responsibility for one's own care can place an additional burden on both patients and their family members.

Throughout the study period, changing experiences between hope and hopelessness related to the received support from healthcare professionals, within and across settings, could lead to frustrations and thoughts about not being able to change anything (Papers 1-3). Thinking in line with Delmar et al. (2005), the pendular movements between feelings of loss of control and control in a life with chronic illness are closely related to the pendular movements between perceptions of hope, doubt and hopelessness. That is, the hope makes us ready to deal with difficult situations in life (Delmar et al. 2005). In contrast, hopelessness can arise when powerlessness cannot be contained (Miller 2000). The significance of this appeared in experiences in which, on the one side, help and support from healthcare professionals contributed to increased motivation and activity, while, on the other side, inadequate or a lack of help and support led to passivity and resignation (Papers 1-3).

The importance of an encouraging approach to participation in healthcare for COPD patients and their family members might be strengthened by a recent Danish nationwide register-based study, which indicates that the course of COPD might be more dynamic than has been assumed up until now (Reilev et al. 2017). Based on a 10-year follow-up period comprising all Danish patients with COPD, who had at least one exacerbation in 2003, the majority of the patients in the general population did not persist with frequent exacerbations as a stable feature of their

disease (Reillev et al. 2017). By way of these results, the picture of COPD as a ruthless progressive illness is shattered. Together with the results of this study, this points towards the need for continuous initiatives within healthcare to treat and support COPD patients and family members in their varied efforts to achieve balance in their lives.

Furthermore, through this study it became evident that the changing experiences between hope and hopelessness in the patients and family members could be influenced by how healthcare professionals paid attention to the area of tension between the hospital, the municipality and the general practitioner (Paper 3). This challenge might be further highlighted in how healthcare professionals from different professions and across five European countries identified limited communication between healthcare providers and limited resources in terms of staff and time constraints as contributory factors in poor quality of care and in fragmented COPD care delivery pathways (Kayyali et al. 2016). In the light of Scheel et al.'s (2008) interactional nursing practice, organizing future healthcare practice to facilitate cooperation between nurses, and interdisciplinary cooperation within and across settings and sectors, might be essential to achieve a more integrated COPD care delivery pathway.

9.5. Reflections on patient and family-centred care within the area of COPD

This study contributes with knowledge about the significance of being met by healthcare professionals who are accommodating and who invite to participation in healthcare, for both patients and their family members, with the aim not only to keep them active and self-managing, but also to sustain hope (Papers 1-3). In the above section, it was suggested that interactional nursing practice could provide a suitable framework for important dimensions of nursing activities, which can be considered to be in line with the attributes of patient and family-centred care (Castro et al. 2016, Scheel et al. 2008). Globally, person-centred care approaches are acknowledged as beneficial in the implementation of supportive self-management interventions (GOLD 2017). Similar to what was valued by the participants in this study, proper support for day-to-day care requires iterative interactions with qualified healthcare professionals (GOLD 2017). Accordingly, the focus of the interactions has to be put on identification of troubles and health beliefs; enhancing intrinsic motivations; mutual goal setting and formulation of strategies; and evaluation and readjustment of these strategies (GOLD 2017). In order to deal with these activities, all three of Scheel's modes of action must come into play, but the mutuality in the dialogue that is required to support this process calls for attention to the aesthetic-expressive mode of action (Scheel et al. 2008).

In the recommendation that healthcare professionals be motivating, engaging, and supportive, the moral-practical mode of action is dominant (GOLD 2017, Scheel et al. 2008). However, this study indicates that limited access to and attention from healthcare professionals meant that patients and family members were not met sufficiently in such an optimal way, and thereby their needs for help and support for daily self-management were not met optimally (Papers 1-3). Based on another study concerned with patient involvement in outpatient follow-up consultations after colorectal cancer surgery, Thomsen et al. (2017) identified two dimensions of patient involvement, which were formulated as treatment-oriented involvement and person-oriented involvement. Patient involvement appeared as a two-way movement between both – the patient was to be engaged in clinical decision-making and for the healthcare professionals to be invited to engage with patients and their relatives' lives and life circumstances. Yet, this process was under the influence of contextual factors, which meant that the treatment-oriented involvement dominated (Thomsen et al. 2017).

If transferred to the COPD patients in the present study, healthcare professionals who led the agenda without being sufficiently open to the sharing of experiences could represent such a contextual factor.

The way that the participants in this study could feel left with too great a responsibility for their own care could indicate that dominance of treatment-oriented involvement presented a challenge for COPD patients and their family members (Papers 1-3). Thomsen et al. (2017) conclude that a more person-oriented involvement may require attention to the development of communicative skills in healthcare professionals who participate in follow-up settings. The results from Thomsen et al.'s (2017) study were limited in context to outpatient follow-up consultations after colorectal cancer surgery. However, considering the above-mentioned challenges, future attention to the development of communicative competences among healthcare professionals, who are involved with COPD patients and their family members, seems relevant too.

9.6. Methodological considerations

The adoption of a Paul Ricoeur-inspired phenomenological-hermeneutic approach throughout the whole study, allowed us to develop knowledge based on the participants' experiences about what it means to participate in healthcare over time in the transitional period after an AECOPD.

The strength of applying Ricoeur's interpretation theory can be shown in what he calls a miracle (Ricoeur 1976, p. 16); the miracle that occurs when human experiences through narration, distanciation, and interpretation are transferred from being private to public (Bruun 2010, Ricoeur 1976). Furthermore, the discussion of the analysis and interpretation of the text material, which have been made in the light of existing knowledge, and philosophical and nursing practice theories, has been fruitful in capturing an enhanced understanding of the "being-in-the-world" as a patient living with COPD and as a family member (Dreyer & Pedersen 2009).

In the following, a further discussion of the considerations regarding the methodological quality of the study will be based on the three criteria: validity, reliability, and generalizability, as they are understood in Kvale & Brinkman's (2009) work on quality in qualitative interview studies. Validity revolves around whether the chosen method investigates what the study focuses on. Reliability concerns the consistency and credibility of the results. In qualitative research, the concept of generalizability can be replaced by the concept of transferability, which includes a discussion about whether and to what extent the results can be transferred to similar individuals or situations (Kvale & Brinkmann 2009).

Validity

Reflexivity

Ongoing reflections upon the quality throughout the study process is important to ensure rigour in qualitative research (Kvale & Brinkmann 2009, Morse et al. 2002). To this end, observation, methodological, and personal notes and a written record were made frequently during each step of the process (Richardson 2000). Furthermore, the researcher, who was also the interviewer, chose to transcribe all the interviews herself. Although this was time-consuming, new reflections were enabled and the process of naïve reading of the text as a whole was facilitated. Through these reflections, the research process was evaluated according to the research questions, and the process was adjusted, where appropriate. For example, amendments to the semi-

structured interview guide from the first to the second round of interviews provided the opportunity to bring into focus issues of importance disclosed by participants.

Furthermore, the results of the analysis and interpretation were discussed within the group of supervisors. During ongoing dialogues, we tried to be open-minded and reflect critically on each other's interpretations. This process constituted an important contribution to the continuing validation of the initial guesses, which were made through the naive reading and the structural analysis (Pedersen 1999). To this end, we made reflections to become more aware of our preconceptions. Moreover, discussing the results of the analysis several times with research fellows within the pulmonary field contributed to a strengthening of the study.

In Kvale & Brinkmann's (2009) thinking, in doing so, we made an attempt to achieve communicative validity, which revolves around testing the validity of gained knowledge and understandings in a mutual dialogue in an appropriate group of researchers. In accord with this, Ricoeur (1976) stated that it is always possible to argue both for and against an interpretation. The results should therefore be considered to represent one possible way of understanding the experiences related to COPD patients' and their family members' participation in healthcare.

Design

The longitudinal design, that involved repeated participant observations and interviews in different contexts conducted over 18 months can be considered a strength of the study (Polit & Beck 2006). The prolonged data collection and the use of serial participant observations and interviews as complementary methods have resulted in rich insights into sensitive and personal issues related to the experience of one's own care (Murray et al. 2009). The benefit of the combination of the two methods can be attributed to the achievement of accounts that include both the participants' actual perceptions and their subsequent recalls related to their participation in healthcare. The repeated data collection made it possible to explore experiences related to the course of the discharge, the recovery, the subsequent daily living, and to the ongoing interaction with the healthcare system. In this way, it was elicited how concerns and considerations related to one's own care could change over time, and how the received healthcare services influenced patients' and families' participation in self-management over time. However, making repeated participant observations and interviews involves a risk of data overload, and thereby a loss of overview of the data material (Morse 1993, Murray et al. 2009). The choice of a limited number of participants can therefore be seen as a strength of the study, while too great a number would imply a risk that the data would not be analysed deeply enough (Kvale & Brinkmann 2009).

Participant observations and interviews

When researchers choose to conduct interviews, the intention is to encourage participants to share with them their experiences and understanding of their current situation. The relationship between the researcher and the participant is crucial as to how this will succeed (Hall 2003). In this study, although it was time consuming, conducting participant observations meant that trust was built up between the participants and researcher, and that a common understanding was reached before the interviews were conducted at home (Pedersen 2012).

However, during the interviews at home, the patient participants could present challenges in how to reflect on their day-to-day care. Similarly, another longitudinal study concerned with self-management in chronic illness found that some of the participants had not discussed their self-management with anyone prior to the interview because, for them, self-management was a more or less automatic behaviour (Audulv 2011). This could explain why, for example, the COPD patients in this study did not talk much about their daily medication, even though they were encouraged thereto by the researcher.

The choice to conduct the interviews at home was made primarily because of a wish to make the situation convenient for the participants and to make space for reflections on sensible topics (Herzog 2005). Furthermore, breathlessness and fatigue would have made it difficult for some of the participants to attend an interview outside of the home, and made them prefer not to leave home (Disler et al. 2012). Being a visitor in a participant's own home can put demands on the interviewer to balance the inherent asymmetry of the relationship between the researcher and the participant (Herzog 2005). In the current study, this was considered in the decisions about whether the patients and the family members should be interviewed individually or together.

As preferred by the participants, most of the interviews were conducted as joint interviews. Other researchers recommend, in the same way, that in cases where both patients and their carers' perspectives are sought, the interviews might be conducted jointly if the participants request it (Kendall et al. 2009, Norlyk et al. 2016). Kendall et al. (2009) point to the cost in conducting a joint interview in that one is less enabled to hear the individual voices of the patient and the family member, and the challenge that it can present in managing information of a sensitive or personal character. In the same way, Norlyk et al. (2016) discuss a dilemma between ethics and methodology, and argue that ethical concerns must be prioritized higher than methodological concerns when interviewing couples. They furthermore put forward that joint interviews of couples potentially could push the data towards shared experiences rather than capturing individual perspectives. The strength of shared experiences, though, lies in how they deepen and broaden the content of the interview data (Norlyk et al. 2016). However, all the patients and the family members who completed the study were met on several occasions, either when they were alone or when they were together.

The combination of individual and shared experiences, hence, provided a complex picture of the individual and joint concerns, considerations and efforts related to their own care. An addition of the healthcare professionals' perspective might have nuanced the picture further (Kendall et al. 2009). The fact that this study is concerned with experiences of the interaction between COPD patients, family members and healthcare professionals indicates the relevance of inclusion of the healthcare professionals' perspective. It is likely that an application of this perspective to the study would have enabled more insight into contradictory or new perspectives on COPD patients' and their family members' participation in the clinical encounter concerned with discharge and self-management support. However, a desire to avoid the risk of overload of data, and to properly manage the time frame of the study, is our justification for the limitation to the two perspectives. Nevertheless, the relevance of the application of the healthcare professionals' perspective points towards future research.

The appropriateness of the predetermined choice of time point for the interviews of six and twelve months after hospitalization, and the chosen six months' interval in between, can furthermore be worthy of reflection. The question is whether the results would have turned out differently with cross cuts at other time points or with shorter intervals. While only some of the patient participants visited the outpatient clinic at the time just after discharge, some of the participants were first met about six months after the discharge. In order to capture better recall of the experience of the transition from hospital to home, an interview after 4-6 weeks

post-discharge would have been more appropriate. Besides, use of more flexibility in the choice of the time points for the interviews might have been a way to adjust the data collection more closely to important transitions and key points in the course of the individual participants' illness (Murray et al. 2009).

Analysis

In this study, it was found appropriate to use a Ricoeur-inspired analysis method with derivation of themes as a way to analyse the great amount of data that were collected in the study period. Murray et al. (2009) argue that the analysis of longitudinal qualitative studies can be time and resource consuming, and that it can be difficult fully to exploit the various analytic opportunities. While an analysis of the transcripts for each person as one longitudinal unit will provide a sense of individual experience, a use of broad thematic approaches can build cross-cutting themes. However, this might be at the expense of the individual contexts (Murray et al. 2009). In the current study, the COPD patients went through different follow-up pathways, and a supplementary analysis and interpretation of one or two cases probably would have contributed with a greater sense of the individual experience related to the context of the individual pathways.

Reliability

The sample

Taking the 30-days mortality of 10% in Denmark after a hospitalization for an AECOPD into consideration (Danish Health Authority 2017b), and in accordance with recent studies, a number of 15 patients and 12 family members was found appropriate (Pinnock et al. 2011). The completion by 10 patients and 5 family members confirmed that the initial number could ensure an appropriate number of participants at the end of the study (Kvale & Brinkmann 2009). All the patients were selected with regard to inclusion criteria, which meant that they all could contribute with knowledge about what it meant to be hospitalized, discharged and to deal with the care of COPD on a daily basis. Furthermore, they all had a close family member, who, to at least some extent, participated in their day-to-day care. The patients were selected consecutively, followed by purposeful sampling, so that their experiences represented both a certain randomness and variation in age and severity of illness (Polit & Beck 2006). It can therefore be considered a strength that the participants were heterogeneous in terms of level of airflow obstruction, age and co-morbidity; nevertheless, they experienced a worsening of their COPD, leading to hospital admission. AECOPD is a known risk factor for poor outcome, but the impact on everyday life after hospital discharge is modifiable by several non-COPD-related factors presented in this study.

The setting

Selecting a respiratory ward as the hospital setting as the starting point for this study turned out to be suitable choice, because it allowed us to achieve an understanding of what was at stake for patients and their family members in participating in their own care before discharge. According to Polit & Beck (2006), the selection of a setting with a good potential for "information richness" is a critical step in the process of sampling.

However, because of breathlessness, fatigue and difficulties in holding a longer conversation, the process of inclusion of patients in the hospital ward became challenging. However, the participant observations and shorter informal interviews made it possible to be considerate to these issues, and leave encouragement of more in-depth elaboration to the subsequent interviews in the participants' homes. Besides inclusion, retention of the participants also presented challenges. In order to keep the participants interested in continued participation in the study, a short telephone call was made about two months before each interview at home. Nonetheless, a certain level of drop-out could not be avoided. Murray et al. (2009) point to attrition as a problem in any longitudinal research and recommend that expected attrition should be factored into the design of the study. As family members, who did not live together with the patient, were the most frequent to drop out in this study, paying more attention to this challenge might be useful in the planning of future research with similar designs.

Transparency

In order to strengthen the reliability, a thorough description of the process of sampling, data collection, and data analysis together with a presentation of the results were given in both the papers and the thesis (Ministry of Higher Education & Science 2014). As a part of the efforts to enhance the quality of the results, data management in the software programme NVivo made it possible to structure the primary data material, and thereby to create a proper basis for the analysis. As a way to enable others to follow the process, the three analytical steps related to the analysis and interpretation were depicted in tables. Moreover, several quotations with careful reference to the kind of participant, setting, time, and method were used in the reporting of the results.

Transferability

A limitation of this study could be that it took its point of departure in a single hospital in a Danish rural context, given that strategies for management of discharge and follow-up could differ between institutions. However, the Danish COPD care delivery pathway follows global recommendations (GOLD 2017), and uses principles in accordance with the internationally used Chronic Care Model (Wagner 1998), and the results of the study might be transferable to similar contexts – both in Denmark and abroad. Furthermore, the results have been supported by the international research literature. The results of this study therefore might raise appropriate questions for further reflections and further research.

Finally, it must be emphasized that the results of this study reflect only the COPD patients' and their family members' experiences in relation to a Western European context. It is likely that COPD patients from other parts of the world have other norms and values regarding their own care. For example, a Taiwanese study demonstrated that cultural factors, such as family kinship and religious beliefs had an influence on patients' self-management behaviours (Chen et al. 2008). In this light, transferability of the results of the present study to other cultures will require additional research.

10. Conclusion

The aim of this longitudinal study was to develop knowledge about the impact of living with COPD by exploring patients' and their family members' experiences related to their participation in healthcare during and after a hospitalization for a severe AECOPD.

The results are remarkable in that they build on experiences from the same COPD patients and their family members during the transitional period related to recovery, discharge, and subsequent daily living – from the time before discharge until 18 months post-discharge. On this basis, the following conclusions can be drawn:

In the transitional period after an AECOPD, participating in healthcare involves seeking to find a balance between feelings of power and powerlessness when participating in decisions about one's own care in the clinical setting at hospital and in the further self-management at home; and to be seen, heard, and understood sufficiently by healthcare professionals to deal with this process.

After the acute phase of the AECOPD, being supported properly in preparations before discharge is essential for patients and their family members to feel ready to take over the responsibility for the day-to-day care at home again. Previous challenges and anxiety in relation to the management of episodes of severe breathlessness was the focal point for the preparatory efforts. For the patients, for whom limited power to engage in their own care dominated, family members could play a central role in ensuring that the patients were seen, heard, and understood.

After returning home, success in having had an influence on the course of discharge and follow-up was of significance to how the patients and family members managed to mobilize power and to achieve a sense of balance. If this was not the case, feeling abandoned and back on their own could be a stressful experience, which could leave patients and their family members discouraged and with long-term perceptions of powerlessness.

In the efforts made to deal with day-to-day care, seeking to balance received advice and encouragement from healthcare professionals with everyday life was important to a persistent experience of health and well-being. Nevertheless, patients struggled to stay active, motivated and confident in their own capacity to self-manage over time. Such negative perceptions related to illness, dilemmas and sad feelings could lead to difficulties in finding proper health-related choices and activities meaningful. Furthermore, the part of the day-to-day care that concerned help-seeking could be associated with doubt and reluctance, and challenge a desire to be as independent as possible.

Furthermore, the way in which the patients and family members perceived the illness and the treatment could differ and affect their family life. A preference for the patients to be reactive in their approach to their own care could stress their family members, who tried to be more proactive. Such diversity could give rise to tensions that had to be navigated. Communicating and sharing their mutual understanding could become difficult over time and affect how the patient felt supported to self-manage, and how the family members managed to contribute thereto.

How the patients and family members manage to deal with their challenges is influenced largely by whether the dialogue with healthcare professionals makes space for a mutual exchange of experiences and reflections, and the negotiation of care plans. If this is not the case, the requirement to face a greater level of responsibility for one's own care can place an additional

burden on both patients and their families. Therefore, adequate support and help must be based on an understanding of matters around readiness, literacy, motivation, competence, confidence, and the impact of illness on family life, and of a professional judgement based on the patients' and family members' concerns, considerations and preferences. Thus, the study adds new knowledge and enhanced understanding, which can be useful for healthcare professionals when providing treatment, care, and support of self-management in relation to discharge and follow-up services to COPD patients and family members.

Moreover, easily accessible healthcare services and alliances can be essential for patients and family members to deal with the many illness-related troubles over time. Nevertheless, navigating different healthcare services, and receiving the help and support as promised, can be a challenge and involve changing feelings of hope and hopelessness in patients and family members.

Thus, with the right service at the right time and place, it might be possible to avoid unnecessary frustration, concerns, and hopelessness, which might affect the subsequent day-to-day care of the illness. This requires that healthcare professionals who enable patient and family participation collaborate with each other, and coordinate healthcare services within and across settings and sectors.

11. Future implications

The results of this study provide a range of perspectives on future clinical practice, education, organization and research.

11.1. Implications for clinical practice

Because the results of this study were obtained from a longitudinal study over an 18-month period, they might point towards a healthcare that would be integrated by a range of components tailored to individual COPD patients' and their family members' need for help and support for better self-management, and which would be provided in partnership with them. As a means to achieve this, the future development and implementation of interventions can draw inspiration from the elements identified by the Chronic Care Model (Wagner 1998).

In a future perspective of prevention and health promotion initiatives to tackle the growing public health problem of COPD, the study might contribute with the following suggestions.

Delivery of adequate care and support of self-management in partnership with patients and family members must allow for the possibility of a two-way movement between "treatment-oriented involvement" and "person-oriented involvement" (Thomsen et al. 2017). Paying attention to the aesthetic-expressive and moral-practical modes of action will help ensure that there is space for "person-oriented involvement." Through the dialogue, patients and family members must be prepared and supported to strengthen their self-management in a way that is in accordance with their preferences and responsive to issues around readiness, motivation, competence, confidence, the role of the family members in the daily care, and the relationship within the family.

In discharge planning, and during follow-up visits at the outpatient clinic, increased focus should be placed on the self-management of exacerbations. Personalized action plans can be an appropriate tool to guide COPD patients in how to monitor their symptoms and in how to manage their medical treatment adequately (Effing et al. 2012). It should be noted that support for patients in their decisions about how and when to seek help must be a part of this plan. This could help alleviate anxiety, doubt and dilemmas, which can occur in relation to help-seeking and involve both patients and family members.

Through iterative interactions, follow-up consultations at the outpatient clinic, with the general practitioner or in a community service, a personalized care plan that involves problem solving, goal setting, and evaluation could contribute to the allocation of appropriate training and supportive interventions, which would be responsive to the patient's changing situation and everyday life. Furthermore, consultations could be organized to use motivational interviewing techniques to uncover the many challenges that patients might have in staying motivated, in the perception of illness and in their approach to self-management (Benzo et al. 2013). With regard to the challenges in health literacy, it might be beneficial to integrate initiatives to improve recall and compliance into future practice (Roberts et al. 2008). In addition, flexible multidisciplinary rehabilitation programmes, telephone follow-up, telemedicine interventions, and case managers, who work across the hospital and home, could be ways to tailor supportive follow-up interventions to the individual.

It is essential that healthcare professionals pay attention to family members' roles and contributions to the COPD patients' struggle with their own care before discharge and with their day-to-day care at home. In cases where family members are involved, healthcare professionals must support and respect them for their expertise. In order to support them

better in their worries and hyper-vigilance, offers of formalized conversations before discharge could be an appropriate solution. A concept as used in an Icelandic conversation intervention for family members during their relative's hospitalization might be a way to deal with the request of family member to discuss their own troubles and support them with the stress and frustrations they experience, which might be related to helping and supporting their ill relative's self-management (Halldórsdóttir & Svavarsdóttir 2012).

However, this study has indicated that there also can be a need to support mutuality and open communication within the family. It could therefore be an idea to offer both the patient and the family member conversations that focus on the family's resources and relationships, and which invites the parties to mutually reflect upon their current situation. Benzein et al. (2008) have developed the concept of a series of nurse-led Family Health Conversations, which can be an appropriate tool to build up a partnership with certain families – such as families in which one person suffers from a chronic illness, and thereby facilitate a context for change. In this concept, families are seen as experts on how to lead their lives and it is acknowledged that they themselves best know how to create new meaning in their lives. Other perspectives for clinical practice could be the establishment of support groups for relatives of COPD patients.

This study draws attention to a need to support COPD patients and family members in a way that facilitates their access to healthcare. An intervention in which they are assisted continuously in learning how to find their way through the health system could be well organized as a community service.

Furthermore, the study points to the way that healthcare is organized as of significance to concerns, frustration and hopelessness in patients and family members. In the current care pathways, services and professional integration between care settings must be a priority (Kayyali et al. 2016). In particular, at the time following a severe AECOPD, coordination of healthcare is essential to the provision of a smooth transition from hospital to home and community. Finally, healthcare organizations must ensure that healthcare provision is designed in a way that enables effective collaboration among healthcare professionals, and between healthcare professionals and COPD patients and family members.

11.2. Implications for education and training

Working in a collaborative and person-centred way means that healthcare professionals have to take an engaging and inviting approach in their interactions with COPD patients and family members. The requirement to encourage more “person-oriented involvement” might lead to a change in the approach to how patients and family members are encountered. As indicated by the results in this study, communication with healthcare professionals was of great importance, in terms of being seen, heard, and understood appropriately. In order to deal better with this challenge, it might be relevant to give healthcare professionals the opportunity for training that would promote their communicative skills in the clinical encounter (Thomsen et al. 2017).

Moreover, increased focus on the involvement of family members might involve a changed view of the family. Seeing the family as a whole and as experts in their own lives might imply new ways to approach and act in the interaction with patients and family members. From an educational perspective, more knowledge about family nursing and family theories could contribute to the development of their competences to engage COPD patients and family members in their own care.

11.3. Implications for future research

With its patient and family perspective, the study points towards future research that involves the family perspective. As a further foundation for the development and evaluation of a family-oriented intervention, a qualitative study of the healthcare professionals' perspective on family participation in healthcare could be relevant. The above suggested implications for practice and education could be the foundation for the initiation of a research programme to implement and evaluate initiatives around facilitated discharge and follow-up across the hospital and community settings. Ideally, the intervention should be graduated and tailored to the individual patient and family after a hospitalization for a severe AECOPD (Trappenburg et al. 2013).

All the suggested initiatives could be relevant, but by virtue of its focus on the conversation between patients and family members, it would seem very appropriate to include the concept of Family Health Conversations in such a research programme (Benzein et al. 2008). Individualised action plans with ongoing support by a case manager, as evaluated positively in a multicentre study, through the transition from hospitalization to the return home for selected patients and family members might be an idea, too (Trappenburg et al. 2011). The implementation of tools to improve health literacy (Roberts et al. 2008) and motivational interviewing (Benzo et al. 2013) also seems to be relevant.

Furthermore, more longitudinal research that involves family members in interventions with a focus on self-management support could be appropriate to inform the form and content of future self-management interventions, such as rehabilitation programmes or telemedicine interventions.

12. English summary

Chronic obstructive pulmonary disease (COPD) represents a major health problem all over the world. Besides, COPD leads to severe morbidity and mortality, it also represents a considerable economic and social burden. In order to deal with these challenges better, the focus on improvement of prevention, treatment, rehabilitation and follow-up of COPD is ongoing. In relation to discharge and follow-up of a hospitalization for a severe acute exacerbation in COPD (AECOPD), the encouragement of greater individual patient and family participation in healthcare in order to strengthen daily self-management at home is an essential part of these efforts. However, for COPD patients and their family members, taking an active approach to their own care can be demanding and the support from healthcare professionals might be insufficient. Furthermore, the implementation of effective self-management interventions remains a challenge. Research within the area that relates to a coherent period following a severe AECOPD, involving the family perspective, is still limited.

Taking this into account, the aim of the study was to develop knowledge about the impact of living with COPD by exploring patients' and their family members' experiences related to their participation in healthcare during and after a hospitalization for a severe AECOPD.

The study adopted a qualitative longitudinal design. A phenomenological-hermeneutic approach inspired by Ricoeur's theory of interpretation guided the study. The study was carried out at a Department of Respiratory Medicine at a regional acute hospital in rural Denmark and in the participants' own homes. In total, 15 patients of both genders, a range of ages and varying severity of COPD were included and followed from the time before discharge to 18 months after. Moreover, 12 family members with different relationships to the patients took part in the study. The data were generated by way of participant observations and informal interviews before discharge and during visits at the pulmonary outpatient clinic. In-depth interviews were performed twice post-discharge. The analysis and interpretation of all data was made on three levels: naïve reading, structural analysis, and critical interpretation and discussion.

The study showed that, for COPD patients and their family members, participating in healthcare in the clinical setting was aimed at gaining power to be able to self-manage day-to-day care at home. However, in the transition from hospital to home and over time, dealing with their own care involved concerns, considerations, dilemmas, frustrations, and tensions within the family, which related to an ongoing struggle to overcome episodes or periods of feeling powerless. Furthermore, to feel supported properly in the struggle it was important to be seen, heard, and understood by healthcare professionals.

Before discharge, participation in healthcare included concerns and doubts about whether and when they were ready to take over the responsibility for their own care at home again. Family members could play an important role in contributing to the preparations before discharge, but did not feel that they were seen sufficiently as a resource by healthcare professionals. At home, the patients strived to stay motivated and confident in their own capacity to self-manage, including deciding when to ask for help. In order to support these efforts, family members sought to help and encourage, but they also made demands on the patient. A preference of patients to demonstrate sedentary and reactive approaches to their own care could stress their family members and give rise to tensions and attempts to navigate between mutual pressure and consideration.

Over time, easily accessible healthcare services, alliances and good interactions with healthcare professionals were important to deal with the many illness-related troubles. However, navigating different follow-up healthcare services and receiving the help and support as hoped for could be demanding and be associated with feelings of both hope and hopelessness.

Based on the results of the study, it can be concluded that with the right service at the right time and place, it might be possible to avoid unnecessary frustration, concerns, and hopelessness, which might affect subsequent day-to-day care. This requires that healthcare professionals who enable patient and family participation collaborate with each other, and coordinate healthcare services within and across settings and sectors.

The results of the study point towards more integrated COPD care pathways across sectors in the future. Person centred approaches that encourage active participation in healthcare should be responsive to COPD patients' and their family members' struggle to balance the self-management of COPD in everyday life.

Furthermore, the results open up initiatives in relation to education and future research. Education with a focus on communicative skills might be relevant in order to improve healthcare professionals' competences to work together with patients and family members.

In relation to future research, longitudinal follow-up research on interventions including family centred care and integrated care solutions across hospital and community services might be appropriate to inform the form and content of future initiatives to improve healthcare around discharge and follow-up.

13. Dansk resumé

Kronisk obstruktiv lungesygdom (KOL) er en sygdom, der udgør en stor sundhedsmæssig udfordring over hele verden. Udover at KOL er en hyppig årsag til sygelighed og dødelighed i den voksne befolkning, repræsenterer sygdommen samtidig en betragtelig økonomisk og social belastning. Med henblik på at håndtere disse udfordringer, er der i Sundhedsvæsenet vedvarende fokus på at optimere forebyggelse, behandling, rehabilitering og opfølgning indenfor KOL-området. Ved udskrivelse og opfølgning efter en indlæggelse på sygehus for en akut episode af svær forværring i KOL, er inddragelse af patienter og pårørende i deres pleje- og behandlingsforløb en vigtig del af den samlede indsats for at styrke dem i deres daglige behandling og håndtering af egen sygdom. Imidlertid kan det for KOL patienter og deres familie medlemmer være krævende at skulle være aktive i egen pleje og behandling, og støtten hertil fra de sundhedsprofessionelle kan opleves utilstrækkelig. Endvidere viser den eksisterende forskning, at implementering af effektive indsatser til opfølgning og støtte af den enkelte i behandling og håndtering af egen sygdom over tid forbliver en udfordring. Indenfor dette område er der ligeledes stadig begrænset forskning, som relaterer sig til en længere sammenhængende periode efter en svær forværring i KOL og som involverer familiens perspektiv.

I betragtning heraf var det formålet at undersøge patienters og pårørendes oplevelser i relation til at være deltagende i pleje og behandling under og efter en indlæggelse for en svær forværring i KOL og derigennem at udvikle viden om betydningen af at leve med KOL.

I undersøgelsen blev der anvendt et kvalitativt longitudinelt design. Til at guide undersøgelsen, blev der anvendt en fænomenologisk-hermeneutisk tilgang, som var inspireret af den franske filosof Paul Ricoeur's fortolkningsteori. Undersøgelsen blev udført i en afdeling for lungemedicinske sygdomme på et regionalt akutsygehus i Danmark, samt i deltagerens eget hjem. I alt blev inkluderet 15 patienter, der repræsenterede begge køn, forskellig aldre og forskellig grad af KOL. Derudover deltog 12 familiemedlemmer med forskellig relation til patienterne. Deltagerne blev fulgt i varierende omfang fra tiden op til udskrivelsen og op til 18 måneder efter. Data blev genereret via deltagerobservationer og uformelle interviews før udskrivelsen og under besøg i det lungemedicinske ambulatorium. Derudover blev der afholdt dybdegående interviews to gange efter udskrivelsen. Dataanalyse og fortolkning foregik på tre niveauer: naïv læsning, strukturanalyse og kritisk fortolkning og diskussion.

Undersøgelsen viste, at deltagelse i egen pleje og behandling i det kliniske møde med de sundhedsprofessionelle for KOL patienter og deres familiemedlemmer var rettet mod at opnå styrke og at blive i stand til at håndtere egen pleje og behandling i hverdagen. Imidlertid, så kunne varetagelsen af egen pleje, både i overgangen fra sygehus til eget hjem og over tid, involvere en vedvarende kamp for at overvinde episoder eller perioder af magtesløshed og hertil følgende bekymringer, overvejelser, dilemmaer, frustrationer og spændinger i familien. Endvidere, for at opleve sig passende understøttet i denne kamp var det vigtigt at blive set, hørt og forstået af de sundhedsprofessionelle.

Før udskrivelsen kunne deltagelse i egen pleje og behandling inkludere bekymringer og tvivl om hvor vidt og hvornår man var parat til at overtage ansvaret for egen pleje og behandling hjemme igen. I den forbindelse kunne familiemedlemmer spille en vigtig rolle i at medvirke i forberedelserne på udskrivelsen, men oplevede, at de ikke blev set tilstrækkeligt som en ressource af de sundhedsprofessionelle. Derhjemme kæmpede patienterne med at holde sig motiveret og at opretholde tiltro til deres egen kapacitet for at håndtere egen pleje og behandling, inklusiv at beslutte hvornår de skulle bede om hjælp. Med henblik på at

understøtte disse bestræbelser forsøgte familiemedlemmerne at hjælpe og opmuntre, men de stillede også krav. Hvis patienterne udviste præference for en inaktiv og reaktiv tilgang til egen pleje og behandling kunne det stresse de pårørende. Dette kunne give anledning til spændinger og besvær med at navigere mellem gensidigt pres og hensyntagen.

Let tilgængelige sundhedstilbud, alliancer og godt samarbejde med sundhedsprofessionelle var over tid væsentlige for kunne håndtere de mange sygdomsmæssige udfordringer. Imidlertid kunne det at navigere imellem sundhedsvæsenets forskellige opfølgende tilbud, og at modtage den hjælp og støtte, som man håbede på, være en udfordring og associeret til følelser af både håb og håbløshed.

På baggrund af undersøgelsens resultater kan det konkluderes, at med den rette indsats på rette tid og sted, så vil der være mulighed for at undgå unødige frustrationer, bekymringer og håbløshed, der indvirker på den efterfølgende daglige egen håndtering af pleje og behandling. Dette kræver, at sundhedsprofessionelle, som muliggør inddragelse af patienter og pårørende, samarbejder med hinanden og koordinerer opfølgende sundhedstilbud indenfor og på tværs af afdelinger og sektorer.

Undersøgelsens resultater peger i retning af behov for en fremadrettet udvikling af mere integrerede KOL pleje- og behandlingsforløb på tværs af sektorer. Personcentrerede tilgange, der opfordrer til aktiv deltagelse i pleje og behandling, må være åbne og opmærksomme på den kamp, som KOL patienter og deres familiemedlemmer søger at balancere mellem håndtering af pleje og behandling og hverdagsliv.

Endvidere åbner undersøgelsens resultater op for tiltag i forhold til både uddannelse og forskning. Uddannelsesmæssige tiltag, som retter fokus på kommunikation, kunne være relevante for at øge de sundhedsprofessionelles kompetencer til at samarbejde med patienter og familiemedlemmer.

I den fremadrettede forskning kunne det være oplagt med longitudinel forskning der følger og evaluerer interventioner, der inkluderer familiecentreret og integreret pleje og behandling på tværs af hospital og kommunale sundhedstilbud. Dette kunne bidrage med ny og vigtig viden om form og indhold for fremtidige initiativer til fremme af pleje og behandling omkring udskrivelse og opfølgning.

14. References

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15. Appendices

- A. Written information to the participants (in Danish)
- B. Informed consent form (in Danish)
- C. Interview guide (in Danish)
- D. Approval from the Danish Data Protection Agency (in Danish)

Medicinsk Afdeling, Slagelse Sygehus og
Enheden OPEN, Klinisk Institut,
Det Sundhedsvidenskabelige Fakultet,
Syddansk Universitet

Information til patienter om projektet:

”Deltagelse i overgange i behandlingsforløb med svær kronisk obstruktiv lungesygdom - set i et brugerperspektiv.”

I Medicinsk Afdeling på Slagelse Sygehus ønsker vi at udføre et forskningsprojekt, som har fokus på, hvordan patienter og pårørende oplever at blive inddraget i pleje og behandling. Som ph.d.-studerende sygeplejerske i afdelingen er jeg ansvarlig for projektet, der gennemføres i samarbejde med forskere på Syddansk Universitet og en lungemedicinsk overlæge fra Næstved Sygehus.

Om projektet

I projektet udføres en videnskabelig undersøgelse blandt flere patienter indlagt med svær kronisk obstruktiv lungesygdom (KOL) på det lungemedicinske afsnit på Slagelse Sygehus. Undersøgelsen har til formål at undersøge, hvordan det opleves at skulle leve med svær kronisk obstruktiv lungesygdom (KOL), og hvilke udfordringer og muligheder, der er forbundet med at deltage i behandlingsforløbet. Samtidig er det hensigten at undersøge, hvordan denne situation opleves af de nærmeste pårørende.

Efter en indlæggelse med KOL i forværring oplever mange at have særlige udfordringer i selv at skulle tage vare på sygdom og behandling i hverdagen – dette berører som oftest både patienter og deres pårørende. Der er i Sundhedsvæsenet stigende opmærksomhed på, at mange familier, hvor den ene part har KOL, har behov for sundhedsprofessionel støtte, der omfatter hele familien og rækker ud i hverdagen. Med henblik på at forbedre fremtidige sundhedstilbud, vil jeg gerne høre om dine erfaringer med at håndtere din sygdomssituation, mens du er indlagt og i hverdagen hjemme bagefter. Det vil derfor være værdifuldt, hvis jeg må følge dig og din nærmeste pårørende under dit sygdomsforløb det næste år?

Hvad indebærer det at deltage i undersøgelsen?

Undersøgelsen består i, at jeg følger dig under indlæggelser og ambulante besøg på lungemedicinsk afsnit. Jeg vil være til stede i situationer, som jeg aftaler nærmere med dig. I den forbindelse vil jeg observere, hvad der sker omkring dig og stille spørgsmål, hvor det er aktuelt.

Dernæst vil jeg interviewe dig to gange indenfor de næste 12 måneder. Jeg vil her stille dig nogle spørgsmål om, hvordan du oplever din situation med sygdom og behandling hjemme i hverdagen.

I forbindelse med indlæggelse, ambulant besøg og interview vil jeg ligeledes bede dig om at udfylde et mindre spørgeskema om, hvordan KOL påvirker dit velbefindende og din hverdag.

Din nærmeste pårørende interviewes også to gange efter denne indlæggelse. Jeg vil derfor anmode om tilladelse til at tage kontakt til din pårørende, som jeg skal informere om undersøgelsen. I kan herefter i fællesskab overveje og beslutte, om I ønsker at deltage i undersøgelsen. Hvis I ønsker at deltage, bedes I begge underskrive vedlagte samtykkeerklæring og aflevere den til mig. Jeg skal bruge dit CPR-nummer til at finde oplysninger vedrørende din diagnose.

Interviewene foregår rent praktisk ved, at jeg kommer på besøg i jeres hjem og taler med jer i ca. 1 time hver på et tidspunkt, der passer jer. Alle samtaler vil forblive fortrolige mellem dig og mig. Samtalerne, der optages elektronisk, og dine svar på spørgeskemaerne indgår i min undersøgelse. Alle oplysninger vil blive præsenteret anonymiserede. Det er frivilligt om I vil deltage i min undersøgelse. Vælger I at deltage, kan I på hvilket som helst tidspunkt i forløbet trække jer ud uden, at det får konsekvenser for din behandling i afdelingen.

På forhånd tak og venlig hilsen

Ingrid Charlotte Andersen, ph.d.-studerende, sygeplejerske, cand. cur.

For nærmere oplysninger kan jeg kontaktes på tlf. 29606239

Medicinsk Afdeling, Slagelse Sygehus og
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Det Sundhedsvidenskabelige Fakultet,
Syddansk Universitet

Information til pårørende om projektet:

”Deltagelse i overgange i behandlingsforløb med svær kronisk obstruktiv lungesygdom - set i et brugerperspektiv.”

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Om projektet

I projektet udføres en videnskabelig undersøgelse blandt flere patienter indlagt med svær kronisk obstruktiv lungesygdom (KOL) på det lungemedicinske afsnit på Slagelse Sygehus. Undersøgelsen har til formål at undersøge, hvordan det opleves at skulle leve med svær kronisk obstruktiv lungesygdom (KOL), og hvilke udfordringer og muligheder, der er forbundet med at deltage i behandlingsforløbet. Samtidig er det hensigten at undersøge, hvordan denne situation opleves af de nærmeste pårørende.

Efter en indlæggelse med KOL i forværring oplever mange at have særlige udfordringer i selv at skulle tage vare på sygdom og behandling i hverdagen – dette berører som oftest både patienter og deres pårørende. Der er i Sundhedsvæsenet stigende opmærksomhed på, at mange familier, hvor den ene part har KOL, har behov for sundhedsprofessionel støtte, der omfatter hele familien og rækker ud i hverdagen. Med henblik på at forbedre fremtidige sundhedstilbud, vil jeg gerne høre om dine erfaringer med at håndtere din og familiens situation, både mens din pårørende er indlagt og i hverdagen hjemme bagefter. Det vil derfor være værdifuldt, hvis jeg må følge jeres forløb gennem det næste år.

Hvad indebærer det at deltage i undersøgelsen?

Undersøgelsen består i, at jeg følger din pårørende, mens denne er indlagt. Jeg vil være til stede i udvalgte situationer og observere, hvad der sker og stille spørgsmål, hvor det er aktuelt. Hvis du er på naturligt besøg hos din pårørende, vil jeg også stille spørgsmål til dig om dine oplevelser af situationen. På samme måde vil jeg være med, hvis I kommer til kontrolbesøg i lungeambulatoriet.

Jeg vil interviewe dig to gange indenfor de næste 12 måneder. Under interviewene vil jeg stille dig nogle spørgsmål om, hvordan det stiller dig som pårørende at skulle støtte op om sygdom og behandling i hverdagen.

Du og din pårørende kan i fællesskab overveje og beslutte, om I ønsker at deltage i undersøgelsen. Hvis I ønsker at deltage, bedes I begge underskrive vedlagte samtykkeerklæring og aflevere den til mig.

Interviewene foregår rent praktisk ved, at jeg kommer på besøg i jeres hjem og taler med jer i ca. 1 time hver på et tidspunkt, der passer jer. Alle samtaler vil forblive fortrolige mellem dig og mig. Samtalerne, der optages elektronisk indgår i min undersøgelse. Alle oplysninger vil blive præsenteret anonymiserede. Det er frivilligt om I vil deltage i min undersøgelse. Vælger I at deltage, kan I på hvilket som helst tidspunkt i forløbet trække jer ud, uden at det får konsekvenser for din pårørendes behandling i afdelingen.

På forhånd tak og venlig hilsen

Ingrid Charlotte Andersen, ph.d.-studerende, sygeplejerske, cand. cur.

For nærmere oplysninger er du velkommen til at kontakte mig på ica@regionsjaelland.dk eller tlf.nr.: 29606239

Medicinsk Afdeling, Slagelse Sygehus og
Enheden OPEN, Klinisk Institut,
Det Sundhedsvidenskabelige Fakultet,
Syddansk Universitet

Informeret samtykke

Patient:

Jeg bekræfter herved, at jeg vil deltage i ph.d.-studerende Ingrid Charlotte Andersens forskningsprojekt:

"Deltagelse i overgange i behandlingsforløb med svær kronisk obstruktiv lungesygdom - set i et brugerperspektiv"

Jeg har modtaget såvel mundtlig som skriftlig information om projektet. Jeg er informeret om, at det er frivilligt at deltage, og at jeg på hvilket som helst tidspunkt før og efter projektet kan trække mig fra deltagelse uden at det vil påvirke den nuværende eller fremtidige behandling af mig eller min pårørende.

CPR-nr.: _____

Navn: _____

Dato: _____ Underskrift: _____

Pårørende:

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Navn: _____

Dato: _____ Underskrift: _____

Interview guide

Interviewguide til 1. interviewrunde ca. et halvt år efter indlæggelse/udskrivelse

Åbnende spørgsmål:

- Kan du/I fortælle mig om, hvordan det er gået siden vi mødtes på sygehuset?
- Er der sket forandringer i måden du/I lever med sygdommen på siden indlæggelsen på Sygehuset? Evt. kan du/I beskrive det nærmere?
- Hvad er du/I særligt optagede af for tiden i forhold til hverdagen med sygdom?

Vejledende spørgsmål:

- Hvordan vil du/I beskrive jeres hverdag med KOL og hvordan klarer du/I at håndtere evt. udfordringer?
- Hvordan går det med at holde øje med sygdommen og behandle sig selv derefter?
- Hvilke oplevelser har du/I af den hjælp og støtte du/I modtager?
- Hvordan oplever du/I at livet med sygdom påvirker familielivet?

- Hvordan oplevede du/I udskrivelsen fra Sygehuset?
- Var der noget der var særligt svært i hverdagen i tiden efter?
- Var der eksempelvis nye tiltag, som var sat i værk på sygehuset, som var til god hjælp eller bød på særlige udfordringer?
- Hvordan oplevede du/I ellers mulighederne for at få støtte i tiden efter?
- Hvordan oplevede du/I den information, som du/I modtog på sygehuset?

- Hvilke erfaringer har du/I med at blive inddraget af for eksempel læger og sygeplejersker i beslutninger vedrørende pleje og behandling f. eks. i planlægningen af udskrivelsen fra sygehuset?
- Kunne noget være anderledes? Er der eksempelvis noget du/I kunne tænke jer at tale med de sundhedsprofessionelle om, som du/I ikke får mulighed for i dag?

Afsluttende spørgsmål:

- Er der noget I gerne vil tilføje eller fortælle om?

Interviewguide til 2. interviewrunde ca. et år efter indlæggelse/inklusion

Åbnende spørgsmål:

- Kan du/I fortælle mig om, hvordan det er gået siden sidst vi mødtes?

Vejledende spørgsmål:

- Sidst talte du/I om de begrænsninger og besværligheder, som du/I oplever i forhold til for eksempel at varetage behandlingen og holde sig aktiv i hverdagen. Kan du/I fortælle noget mere om det i dag?
- Har det været nødvendigt at ændre noget – fortæl evt. om det?
- Er der nogle særlige oplevelser, som du/I kan berette i den forbindelse?
- Hvordan oplever du/I at livet med sygdom påvirker familielivet?

- Hvordan oplever du/I at kontakten til sundhedsvæsenet er nu? Hvem følger og hvordan følges op, når der er problemer i forhold til sygdommen?
- Hvordan søger du/I viden, hvis der er noget du/I bliver i tvivl om eller gerne vil vide mere om?
- Var der noget du/I kunne tænke jer anderledes?

- Hvad med fremtiden og behandlingen fremover, er det noget du/I har tænkt på og eller taler om?

Afsluttende spørgsmål:

- Er der noget du/I gerne vil fortælle mere om?
- Hvordan har det været at blive fulgt og interviewet af mig i løbet af det sidste år?



Slagelse Sygehus
Medicinsk Afdeling
Ph.d.-studerende
Ingrid Charlotte Andersen
Ingemannsvej 18
4200 Slagelse

Dato: 24.06.2014

Sagsnummer: 12-000179
Initialer: lglu

**Godkendelse af projekt, REG-57-2014:
“Deltagelse i overgange i behandlingsforløb med svær kronisk obstruktiv lungesygdom – set i et brugerperspektiv”.**

Ovennævnte projekt er anmeldt til Region Sjælland efter persondatalovens¹ § 43.

Det fremgår af anmeldelsen, at du er dataansvarlig for projektets oplysninger. Behandlingen af oplysningerne ønskes påbegyndt den 01.06.2014 og forventes at ophøre den 01.06.2017.

Oplysningerne vil blive behandlet på følgende adresse: *Dataansvarlig: Ph.d.-studerende, Ingrid Charlotte Andersen, Medicinsk Afdeling, Slagelse Sygehus, Ingemannsvej 18, 4200 Slagelse.*

PFI
Den Regionale Forskningsenhed
Ny Østergade 12, 2. sal
4000 Roskilde
Tlf.: 47 32 19 10
E-mail: reg.forsk@regionsjaelland.dk

Direkte tlf.: 47 32 19 10
E-mail: lglu@regionsjaelland.dk

www.regionsjaelland.dk/forskning

TILLADELSE

Region Sjælland meddeler hermed tilladelse til projektets gennemførelse, jf. persondatalovens § 43, under Datatilsynets paraplygodkendelse, jf. j.nr. 2008-58-0020 (Region Sjællands j.nr. 12-000179).

Region Sjællands paraplygodkendelse fra Datatilsynet kan downloades herfra:

<https://anmeld.datatilsynet.dk/frontend/fortegnelse/vis.off.asp?pub=yes&myid=71508&m>

Internt har projektet fået sagsnummeret REG-57-2014. Region Sjælland fastsætter i den forbindelse nedenstående vilkår:

¹ Lov nr. 429 af 31. maj 2000 om behandling af personoplysninger med senere ændringer.

Generelle vilkår

Tilladelsen gælder indtil: Den 01.06.2017.

Ved tilladelsens udløb skal du særligt være opmærksom på følgende:

Hvis du ikke inden denne dato har fået tilladelsen forlænget, går Region Sjælland ud fra, at projektet er afsluttet, og at personoplysningerne er slettet, anonymiseret, tilintetgjort eller overført til arkiv, jf. nedenstående vilkår vedrørende projektets afslutning.

Region Sjælland gør samtidig opmærksom på, at al behandling (herunder også opbevaring) af personoplysninger efter tilladelsens udløb er en overtrædelse af persondataloven, jf. § 70.

1. *Ph.d.-studerende, Ingrid Charlotte Andersen* er ansvarlig for overholdelsen af de fastsatte vilkår.
2. Oplysningerne må kun anvendes til brug for projektets gennemførelse.
3. Behandling af personoplysninger må kun foretages af den dataansvarlige eller på foranledning af den dataansvarlige og på dennes ansvar.
4. Enhver, der foretager behandling af projektets oplysninger, skal være bekendt med de fastsatte vilkår.
5. De fastsatte vilkår skal tillige iagttages ved behandling, der foretages af databehandler.
6. Lokaler, der benyttes til opbevaring og behandling af projektets oplysninger, skal være indrettet med henblik på at forhindre uvedkommende adgang.
7. Behandling af oplysninger skal tilrettelægges således, at oplysningerne ikke hændeligt eller ulovligt tilintetgøres, fortabes eller forringes. Der skal endvidere foretages den fornødne kontrol for at sikre, at der ikke behandles urigtige eller vildledende oplysninger. Urigtige eller vildledende oplysninger eller oplysninger, som er behandlet i strid med loven eller disse vilkår, skal berigtiges eller slettes.
8. Oplysninger må ikke opbevares på en måde, der giver mulighed for at identificere de registrerede i et længere tidsrum end det, der er nødvendigt af hensyn til projektets gennemførelse.
9. En eventuel offentliggørelse af undersøgelsens resultater må ikke ske på en sådan måde, at det er muligt at identificere enkeltpersoner.
10. Eventuelle vilkår, der fastsættes efter anden lovgivning, forudsættes overholdt.

Elektroniske oplysninger – krav til sikkerhed

11. Identifikationsoplysninger skal krypteres eller erstattes af et kodenummer el. lign. Alternativt kan alle oplysninger lagres krypteret. Krypteringsnøgle, kodenøgle m.v. skal opbevares forsvarligt og adskilt fra personoplysningerne.
12. Adgangen til projektdata må kun finde sted ved benyttelse af et fortroligt password. Password skal udskiftes mindst én gang om året, og når forholdene tilsiger det.

13. Ved overførsel af personhenførbare oplysninger via Internet eller andet eksternt netværk skal der træffes de fornødne sikkerhedsforanstaltninger mod, at oplysningerne kommer til uvedkommendes kendskab. Oplysningerne skal som minimum være forsvarligt krypteret under hele transmissionen. Ved anvendelse af interne net skal det sikres, at uvedkommende ikke kan få adgang til oplysningerne.
14. Udtagelige lagringsmedier, sikkerhedskopier af data m.v. skal opbevares forsvarligt aflåst og således, at uvedkommende ikke kan få adgang til oplysningerne.

Manuelle oplysninger – krav til sikkerhed

15. Manuelt projektmateriale, udskrifter, fejl- og kontrollister, m.v., der direkte eller indirekte kan henføres til bestemte personer, skal opbevares forsvarligt aflåst og på en sådan måde, at uvedkommende ikke kan gøre sig bekendt med indholdet.

Oplysningspligt over for den registrerede

16. Hvis der skal indsamles oplysninger hos den registrerede (ved interview, spørgeskema, klinisk eller paraklinisk undersøgelse, behandling, observation m.v.) skal der uddeles/fremsendes nærmere information om projektet. Den registrerede skal heri oplyses om den dataansvarliges navn, formålet med projektet, at det er frivilligt at deltage, og at et samtykke til deltagelse til enhver tid kan trækkes tilbage. Hvis oplysningerne skal videregives til brug i anden videnskabelig eller statistisk sammenhæng, skal der også oplyses om formålet med videregivelsen samt modtagerens identitet.
17. Den registrerede skal endvidere oplyses om, at projektet er anmeldt til Region Sjælland efter persondataloven, samt at Region Sjælland har fastsat nærmere vilkår for projektet til beskyttelse af den registreredes privatliv jf. persondataloven.

Indsigtsret

18. Den registrerede har ikke krav på indsigt i de oplysninger, der behandles om den pågældende.

Videregivelse

19. Videregivelse af personhenførbare oplysninger til tredjepart må kun ske til brug i andet statistisk eller videnskabeligt øjemed.
20. Videregivelse må kun ske efter forudgående tilladelse fra Region Sjælland. Bemærk, at Region Sjælland kan stille nærmere vilkår for videregivelsen samt for modtagerens behandling af oplysningerne.

Ændringer i projektet

21. Væsentlige ændringer i projektet skal anmeldes til Region Sjælland (som ændring af eksisterende anmeldelse). Ændringer af mindre væsentlig betydning kan meddeles Region Sjælland.
22. *Ændring af tidspunktet for projektets afslutning skal altid anmeldes.*

Ved projektets afslutning

23. *Senest ved projektets afslutning skal oplysningerne slettes, anonymiseres eller tilintetgøres, således at det efterfølgende ikke er muligt at identificere enkeltpersoner, der indgår i undersøgelsen.*
24. Alternativt kan oplysningerne overføres til videre opbevaring i Statens Arkiver (herunder Dansk Dataarkiv) efter arkivlovens regler.

25. Sletning af oplysninger fra elektroniske medier skal ske på en sådan måde, at oplysningerne ikke kan genetableres.

Ovenstående vilkår er gældende indtil videre. Region Sjælland forbeholder sig ret til senere at tage vilkårene op til revision, hvis der skulle vise sig behov for det.

Særlige vilkår

-

Opmærksomheden henledes specielt på, at Region Sjællands vilkår også skal iagttages ved behandling af oplysninger på de deltagende centre mv., jf. de generelle vilkår nr. 4.

Region Sjælland gør opmærksom på, at denne tilladelse alene er en tilladelse til at behandle personoplysninger i forbindelse med projektets gennemførelse. Tilladelsen indebærer således ikke en forpligtelse for myndigheder, virksomheder m.v. til at udlevere eventuelle oplysninger til dig til brug for projektet.

En videregivelse af oplysninger fra statistiske registre, videnskabelige projekter m.v. kræver dog, at den dataansvarlige har indhentet særlig tilladelse hertil fra Region Sjælland, jf. persondatalovens § 10, stk. 3.

Region Sjælland skal for god ordens skyld også gøre opmærksom på, at der i sundhedslovens § 46 findes særlige regler om videregivelse fra patientjournaler til forskning, herunder regler om Sundhedsstyrelsens godkendelse.

Anmeldelsen offentliggøres i fortegnelsen over anmeldte behandlinger på Datatilsynets hjemmeside **www.datatilsynet.dk**.

Persondataloven kan læses/hentes på Datatilsynets hjemmeside under punktet "Lovgivning".

Advarsel – ved brug af Excel, PowerPoint m.v.

Den dataansvarlige skal til enhver tid sikre sig, at dokumenter og andre præsentationer, som publiceres eller på anden måde gøres tilgængelig for andre på internettet, usb-nøgle eller på andet elektronisk medie, ikke indeholder personoplysninger.

Der skal vises særlig agtpågivenhed i forbindelse med brug af grafiske præsentationer i Excel og PowerPoint, da de uforvarende kan indeholde indlejrede persondata i form af regneark, tabeller mv. Præsentationer, der gøres tilgængelig på internettet, bør derfor omformateres til Portable Digital Format (PDF), da dette fjerner eventuelle indlejrede Excel-tabeller.

Med venlig hilsen

Lia Giarbini Lund
Forskningssekretær

16. Papers

Paper 1

Andersen, I.C., Thomsen, T.G., Bruun, P., Bodtger, U., & Hounsgaard, L.: The experience of being a participant in one's own care at discharge and at home, following a severe acute exacerbation in COPD: a longitudinal study. *Resubmitted*.

The paper has been revised and published online 06 September 2017: International Journal of Qualitative Studies on Health and Well-being; DOI.org/10.1080/17482631.2017.1371994.

Paper 2

Andersen, I.C., Thomsen, T.G., Bruun, P., Bodtger, U., & Hounsgaard, L.: Patients' and their family members' experiences of participation in care following an acute exacerbation in COPD: a phenomenological-hermeneutic study. *Journal of Clinical Nursing. Accepted: 07 July 2017. DOI: 10.1111/jocn. 13963.*

Paper 3

Andersen, I.C., Thomsen, T.G., Bruun, P., Bodtger, U., & Hounsgaard, L.: Between hope and hopelessness: COPD patients' and their family members' experiences of interacting with healthcare providers – a qualitative longitudinal study. *Submitted*.