



# **Women's experiences of living with chronic obstructive pulmonary disease stage III or IV and the experiences of their close relatives**

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## Women's experiences of living with chronic obstructive pulmonary disease stage III or IV and the experiences of their close relatives

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To my family









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# Abstract

This doctoral thesis is in nursing and the overall aim was to explore, describe, and generate knowledge about women's experiences of living with chronic obstructive pulmonary disease (COPD) stages III or IV, and about the experiences of their close relatives. Living with a serious long-term illness such as COPD profoundly affects a person's everyday life and thereby their health and well-being. Data have been collected through qualitative individual interviews (I, IV) and narrative interviews (II, III). The interviews have been analyzed via qualitative content analysis (I, IV) and phenomenological hermeneutical interpretation (II, III). The findings show that women with COPD stage III or IV and their close relatives experienced both suffering and moments of health during their everyday lives (I-IV), despite the unpredictability of their severe illness and their ever-present breathlessness (I). Women were the experts of their own illness, managing their everyday lives to enable moments of feeling well (II). In addition, being seen as diagnosis rather than as a person made the women feel ignored by healthcare personnel which influenced their health and well-being in negative way (III). Close relatives experienced difficulties in fully understanding the women's struggle of living with COPD. In efforts to comprehend their ill health and stress, they must contend with a lack of tailored information and uncertainty while providing practical and emotional support (IV). The findings in this doctoral thesis show that women with COPD stages III or IV were living with an unpredictable ever-present breathlessness that causes suffering in their everyday lives. Despite this woman experienced moments of feeling well. Meanings of healthcare encounters for women with COPD stage III or IV showed that women wished to be seen as a person and not as a diagnosis. Feeling disrespected and unjust leaves women unsupported and could mean serious health

risks. Close relatives asked for tailormade information and knowledge to further understand women's ill health.

Keywords: chronic obstructive pulmonary disease; confirmation; everyday life; experiences; healthcare encounters; health; interviews; lived experience; phenomenological hermeneutics; qualitative content analysis; well-being; women.





# List of papers

This doctoral thesis is based on the following studies, referred to in the text by their Roman numerals. Reprints were made with permission from the publisher of Paper I, II and IV.

- I. Ekdahl, A., Söderberg, S., & Rising-Holmström, M. (2021). Living with an ever-present breathlessness: Women's experiences of living with chronic obstructive pulmonary disease stage III or IV. *Scandinavian Journal of Caring Sciences*, 36(4), 1064–1073. <https://doi.org/10.1111/scs.12998>
- II. Ekdahl, A., Söderberg, S., & Holmström Rising, M. (2023). Striving for moments of easier breathing despite being trapped in breathlessness: meanings of feeling well for women with chronic obstructive pulmonary disease stage III or IV. *International Journal of Qualitative Studies on Health and Well-being*, 18(1), 2225937. <https://doi.org/10.1080/17482631.2023.2225937>
- III. Ekdahl, A., Söderberg, S., & Holmström Rising, M. (submitted). Being met as a person and not as a diagnosis: meanings of healthcare encounters for women with chronic obstructive pulmonary disease grade III or IV.
- IV. Ekdahl, A., Söderberg, S., & Holmström Rising, M. (2023). The experiences of close relatives to women with chronic obstructive pulmonary disease stages III or IV: A qualitative study. *Nursing Reports*, 13(3), 982–990. <https://doi.org/10.3390/nursrep13030086>





# Abbreviations and definitions

**COPD** Chronic Obstructive Pulmonary Disease (COPD) is a heterogeneous lung condition, characterized by chronic respiratory symptoms (dyspnoea, cough, sputum production and/or exacerbations) due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive, airflow obstruction (GOLD, 2023).

## **COPD severity**

GOLD (2023) classifies COPD severity in four stages: stage I is mild, stage II is moderate, stage III is severe, and stage IV represents very severe COPD.

**GOLD** Global Initiative for Chronic Obstructive Pulmonary Disease.

# Preface

My interest in long-term illnesses has developed during my lengthy clinical experience as a registered nurse. I worked for many years with people who have a variety of long-term illnesses in inpatient and outpatient settings. Later, I worked as a research nurse in clinical trials involving people with long-term illnesses, mostly cancer. I learned much about the research process and systematic procedures, and my curiosity grew. Clinical trials involving people with cancer, women with breast cancer in particular, often include individuals with advanced disease, where cure is not possible. Meeting with such women and their relatives over time has provided me insights and generated fascination regarding what registered nurses can do to promote health and well-being until the end of life for individuals with advanced long-term illness. As a research nurse, I had sufficient time to spend on each person that many confirmed to me they felt content with the care I delivered. My team and I maintained a working environment and culture that provided opportunities to create relationships between myself, the person, and their close relatives; this enabled me to build trust, hope, and space to listen to their desires and fears. I developed endurance to be present and listen, which has later been useful in other aspects of my life and research. In contrast to providing care to people with severe long-term illnesses, another part of my long experience has been as a breast cancer nurse in surgical outpatient reception. This has further widened my knowledge, by enabling me to meet women who mostly had early and curable breast cancer. My work in this area often dealt with managing shock reactions, uncertainty, and fear of cancer recurrence, and with supporting the patients' psychosocial and working lives. Alongside my clinical work, I have consistently and voluntarily taken university courses, including cardiology, nephrology, oncology, research methodology, and nursing.

My ambition eventually led me to pursue the third cycle of education. My earlier career experiences have continued to inspire and drive my enthusiasm for this work and this doctoral thesis.



# Introduction

This doctoral thesis is in nursing; it focuses on women's experiences of living with the long-term illness of chronic obstructive pulmonary disease (COPD) stages III or IV, and the experiences of their close relatives. The metaparadigm of nursing contains four concepts: humans, health, environment, and nursing interventions (cf. Fawcett, 1984). Eriksson (2018) has stated that health, a natural phenomenon within all people's lives, is the main purpose of nursing. Meanwhile, people are living longer than in the past, and the population older than 65 is increasing worldwide. In parallel, the number of people diagnosed with long-term illnesses is also rising, per the World Health Organization (WHO, 2023). According to the Global Initiative for Chronic Obstructive Lung Disease (GOLD, 2023), COPD is a common long-term illness, and is a major cause of chronic morbidity and mortality around the world. In addition, globally, women face vulnerability to their health in a variety of areas (WHO, 2023). Women with COPD constitute a vulnerable group affected not only by symptoms related to the course of their illness, but also by behavioural, socioeconomic, sociocultural, environmental, and biological factors (Axelsson-Fisk, 2021; GOLD, 2023). The focus of this doctoral thesis is to explore, describe, and generate knowledge about the illness experiences of women with COPD at stages III or IV, and the experiences of their close relatives. Because COPD is a complex illness that influences almost every aspect of everyday life, it seems appropriate to generate further knowledge regarding the experiences of living with COPD at stages III or IV, from the perspectives of women who have the illness and their close relatives.

# Background

## Health and ill health for people with long-term illness in nursing

Health is a fundamental human right, and health equity is achieved when everyone can attain their full potential for health and well-being. Health is also a universal aspect of humanity, although the conception and views of it vary among different disciplines and research fields (cf. Arman, 2015; WHO, 2023). One of the metaparadigms in nursing is the concept of health, which Eriksson (2014) describes as a condition or process expressed as “having health” or as to “be healthy”. Further, Eriksson (2018) defines the concept of illness as a person’s subjective experience of ill health: It is not possible to give health to another person, but it is possible to support a person in becoming healthy. Health is a complex and multifaceted phenomenon that involves physical, mental, and social well-being, not simply the absence of disease. Even while living with illness, people can still experience health. Eriksson (2018) argues that health is relative and varies based on time and space; includes individual past societal, cultural, and knowledgeable experiences; and differs in specific context. One component of health is suffering, and Eriksson (2018) holds the view that suffering and health can coexist; even during suffering, a person can still experience health. Suffering can violate human dignity, but also can bring renewal and reconciliation. Eriksson (2018) categorizes three types of suffering: suffering of illness, suffering of care, and suffering of life.

For people living with long-term illnesses such as COPD, experiences of ill health tend to be due to losses of bodily functions, loss of abilities, and deterioration (GOLD, 2023). The health and well-being of people living with such long-term illnesses are affected in various ways. However, accepting, adjusting, and replacing previous activities with other meaningful ones can make social, physical, and emotional well-being possible (Stridsman et al., 2015a; Dobler, 2019; Philip et al., 2019). Different factors seem to contribute to subjective well-being (Steptoe, 2019); for example, life circumstances, behaviour, and environment may all have effects. To improve well-being, additional values could be of importance, such as experiencing positive relationships and a thriving social life (Moons, 2006; Eid & Larsen, 2008). According to Jenkinson and Cantrell (2017), women with long-term illnesses who foster and utilize their inner strength are inclined towards well-being, which facilitates their health. Support in the form of teamwork for people with long-term illnesses is another commonly applied approach to promoting perceived health and well-being (Gardener et al., 2018).

According to Toombs (1995), the experience of illness is subjective, based on how an individual's illness is understood in everyday life. Living with a long-term illness can be experienced as a threat to the self (Toombs, 1992). People with long-term illness can achieve well-being, a sense of meaning, and dignity by having someone with whom they can share their losses and difficult experiences; this can help them carry on living and seek to restore their health even during severe illness (Toombs, 1995). Confirmation and explanation of the illness experience can provide some relief from what a given illness involves (Toombs, 1992). Knowledge about the illness experience is a prerequisite for nurses and other healthcare personnel, for meeting the needs of ill people and their close relatives and thereby an opportunity to design individual nursing care.

## People living with long-term illness

People living with long-term illnesses deal with complex changes in everyday life due to their diseases. Previous research examining people with long-term illnesses shows that hindrances to the ability to take everyday life for granted include experiences of uncertainty, loss of control, dependence, sorrow, worries, loneliness, vulnerability, and unpredictability. Such studies indicate people living with long-term illness naturally attain expertise through a process involving trial and error, gaining awareness, gathering knowledge, and lived experiences (Chen et al., 2016; Olano-Lizarraga et al., 2016; Smit et al., 2019; Hosono & Tochikawa, 2022; GOLD, 2023). When a person is diagnosed with a long-term illness, their healthcare needs often increase periodically; if the illness is incurable and deteriorating, such as in COPD stages III or IV, their needs for assistance will progress (GOLD, 2023). In helping people navigate the challenges of long-term illness, close relatives are important. Furthermore, support through education, information and better understanding for patients and their close relatives, though this empowers people living with long-term and serious illnesses. This contributes a better everyday life (Kralik, 2001; Kralik, 2002; Öhman et al., 2003; Kralik et al., 2004; Ahlström, 2007; Lundman & Janson 2007; Nätterlund, 2010; Olano-Lizarraga et al., 2016; King et al., 2023; Holmlund et al., 2023). Research has described additional types of support as helpful to people with long-term illnesses, including holding religious faith, experiencing positive human relationships, visiting the countryside, and enjoying memories of the past. In addition, people living with long-term illnesses have described the abilities to work and feel independent as highly valuable (Entwistle et al., 2018; Nilsson et al., 2019).



## Women living with long-term illness

Throughout the world, women face vulnerabilities to their health in a variety of areas, such as limited education, impeded social status, other types of gender discrimination, and domestic violence. These factors hinder women's abilities to fulfil their life goals and access necessary healthcare services (Downs et al., 2014; Langer et al., 2015; Axelsson-Fisk, 2021; WHO, 2023). Women with COPD experience heavy symptom burdens, which are exacerbated by social, economic, and pollution-related factors, alongside racial disparities (Aryal et al., 2014; Adeloje et al., 2015; Raghvan et al., 2017; DeMeo et al., 2018; Gut-Gobert et al., 2019; Vanfleteren et al., 2020; Buttery et al., 2021; WHO, 2021).

Globally, the most common long-term illnesses in women include cancer, stroke, mental health disorders, diabetes, cardiovascular diseases, comorbidity of cardiovascular and COPD (WHO, 2023; Osika Friberg et al., 2016). Cardiovascular illnesses are the leading cause of death among women, and are under-diagnosed, under-studied, under-recognized, and under-treated (Vogel et al., 2021). Women living with physical disabilities have an even greater risk than others of developing cardiovascular diseases, and may be forgotten during discussions of equity and inclusion (Parry et al., 2021). Meanwhile, women with breast cancer are likely to experience serious depression, which affects their everyday lives (Javan Biparva et al., 2023). In addition, diagnosis of stroke in women can often be delayed compared to that in men. Women also experience such symptoms as nausea, vomiting, headache, dizziness, and cognitive dysfunction more often than men (Colsch & Lindseth, 2018). Further, women living with diabetes have more to manage in daily life, due to higher risks of complications such as heart disease, blindness, kidney disease, and depression. Worldwide, women of African-American, Hispanic/Latina,

American Indian/Alaska Native, and Asian/Pacific Islander descent are more likely to have diabetes than white women (Tomick et al., 2022). According to Smirthwaite (2016), women also tend to experience longer wait times for cataract surgery compared to men.

Chronic obstructive pulmonary disease is increasingly recognized as a major women's health concern, with high prevalence and mortality (Ntritsos et al., 2018). According to the United Nations (UN, 2015), COPD is the leading cause of death among women in the USA. Women are more vulnerable to the harmful effects of tobacco smoking compared to men. Women with COPD also experience more severe symptoms, and more frequently report shortness of breath due to their smaller airways. Their other symptoms tend to include lower body weight, higher frequency of exacerbations, and reduced qualities of both life and self-rated health (GOLD, 2023). In addition, it is widely understood that women continue to experience the majority of "nameless conditions" (Malterud, 1987), although women tend to report higher total prevalence of symptoms than men, and ask more questions during healthcare encounters (Bardel et al., 2019).

In Sweden, women's health issues are dominated by mental illness, stress-related illness, musculoskeletal pain, and chronic pain, all of which lead to suffering. The rate of sick leave for women in Sweden is almost twice as high as that for men (Statistics Sweden, 2022). Moreover, reproductive health and ill health are biologically connected to the female sex and hormones, and thereby natural and highly common among women. However, women's experiences of ill health can cause distress, severely affecting their everyday lives and health (Osika Friberg et al., 2016; cf. Toye et al., 2017; Arman et al., 2020; Osborn et al., 2020). In addition, gender-based differences occur in pharmaceutical treatment, to the detriment of women on the historical basis of their exclusion from clinical trials (Merkatz et al., 1993). One

step to counteract this is the initiative of the database Janusmed Sex and Gender, which could improve drug safety by highlighting individualized treatment for both men and women (Karlsson Lind et al., 2023).

## Chronic obstructive pulmonary disease -a long-term illness

Chronic obstructive pulmonary disease is a common long-term illness, with a prevalence of 10% among the global population (GOLD, 2023). The prevalence of COPD in Sweden is 7–10% among people over 40 years old, and the incidence of people with COPD at stages II and III is 3–5% (Backman et al., 2020). The mortality of COPD is expected to reach the third most common cause of death worldwide by 2030, although this will vary across countries; 90% of COPD-related deaths occur in low-and middle-income countries (Halpin et al., 2019; Meghji et al., 2021; GOLD, 2023). Globally, the most common factor in development of COPD is tobacco smoking. However, approximately 20% of people with COPD have never smoked (Hagstad et al., 2014; Hagstad et al., 2015). Other risks are connected to indoor air pollution, outdoor air pollution, occupational exposures, genetic factors, age, sex (with an increased risk for women), history of severe infections affecting lung function, and asthma. In Sweden, tobacco smoking is the primary risk factor of developing COPD, and approximately 50% of smokers develop the disease. However, tobacco use in Sweden has decreased from 30% in the 1980s to 6% in recent years (Backman et al., 2020). GOLD (2023) classifies COPD into four stages (Table 1).

Table 1. *Classification for COPD by stage, grade and FEV<sub>1</sub> (GOLD, 2023)*

<b>GOLD Stage</b>	<b>Grade</b>	<b>FEV<sub>1</sub> (Forced Expiratory Volume 1 sec. i.e. assessment of airflow limitation)</b>
I	Mild	≥ 80
II	Moderate	50–79
III	Severe	30–49
IV	Very severe	< 30

According to Sandelowsky et al. (2016), 90% of COPD diagnoses are performed in primary care, although diagnosis demands a thorough medical history examination due to the complexity of COPD. Nevertheless, moderate to severe COPD is underdiagnosed (Axelsson et al., 2023). The disease is generally mild initially, but is progressive and incurable. Common symptoms of COPD at stages III or IV are cough and sputum production, fatigue, and breathlessness, which cause feelings of anxiety and suffocation (Connolly & Yohannes, 2016; Adeloje et al., 2022; Farver-Vestergaard et al., 2022; Christiansen et al., 2023; GOLD, 2023). Comorbidities with COPD at stages III or IV are both highly common and complex; for example, asthma, heart failure, lung cancer, depression, musculoskeletal effects, cognition impairment, and nutritional status problems may occur (Aryal et al., 2014; Sawahla et al., 2019). One approach to reducing the natural progression of COPD is to focus on smoking cessation. Key treatment

options to reduce risk of death, manage symptoms, and increase health status for people with COPD include pharmacological treatment and vaccinations (GOLD, 2023). Research has also identified a connection between low physical performance and sedentary lifestyles, which lead to fatigue and breathlessness; hence, pulmonary rehabilitation is also important (Long et al., 2019; Sandelowsky et al., 2019; Ter Beek et al., 2020). 'Exacerbations' describe a deterioration of COPD, causing dyspnoea, cough, and mucus, and are often caused by bacterial infections (approximately 50%) and viral infections that can lead to secondary bacterial infections (Avadhanula et al., 2006). Oxygen treatment is highly common for patients with COPD at stage IV, as it reduce symptoms and prolongs life expectancy (Maddocks et al., 2017; Jacobs, 2020; Mao et al., 2022). Surgical treatment, invasive ventilation, non-invasive ventilation, and transplantation comprise further possibilities for treating people with advanced COPD, to unburden their breathing (Uronis et al., 2015; Raveling et al., 2021). Palliative care is central during the more severe stages, and focuses on supportive approaches and alleviation of symptoms, which can include pain, emaciation, cough, insomnia, breathlessness, and depression (Ekström et al., 2015; Maddocks et al., 2017; Maddocks et al., 2019).

# Living with chronic obstructive pulmonary disease

Everyday life for people with COPD involves unpredictable bodily changes, and reduced well-being that can cause disabilities on the physical, psychological, and social levels. In turn, this leads to a withdrawal from the outside world, invisible breathlessness, and existential suffering (Farquhar et al., 2018; Ali et al., 2018; Van der Meide et al., 2020; Serresse et al., 2022; GOLD, 2023).

People living with COPD at stages III or IV experience challenging limitations due to fluctuating breathlessness, in ways that shape their everyday lives (Ek et al., 2011). This contributes to feelings of anxiety and helplessness, and sometimes a sensation of suffocation (Stridsman et al., 2015b; Miravittles & Ribera, 2017; Johansson et al., 2019). According to Van der Meide et al. (2020) and Harrison et al. (2015), feeling helpless due to breathlessness can aggravate feelings of unworthiness.

People living with COPD at stages III or IV have described their experiences as influencing almost every aspect of their daily life activities, or as living in a controlled co-existence with the illness. Essentially, everyday life with severe COPD constitutes managing a spectrum of breathlessness, from lighter forms to heavier feelings of panic or suffocation (Disler, 2014). Breathlessness is a frightening sensation, and a predictor not only of reduced quality of life but also of mortality, as people tend to avoid activities that cause breathlessness and thereby speed illness progression (Parshall, 2012; Waschki et al., 2015; Stoeckel et al., 2018). Physiological breathlessness can be triggered by both emotional anticipation and physical inducement (Christiansen et al., 2023). Managing this symptom includes knowing what works, such as using inhalers, practicing lip breathing techniques,

adjusting oxygen treatment, sitting in a comfortable position, and remaining focused on reducing breathlessness. People with COPD who have maintained everyday life chores and performed achievable activities have reported this approach brought them a sense of control, although these maintenance steps demanded all of their energy. They have also expressed that family, friends, and healthcare personnel supports are important (Disler et al., 2012).

During the COVID-19 pandemic, people with COPD have comprised an especially vulnerable group, associated with increased isolation in their homes, anxiety, fear of limited access to or denial of healthcare, and fear of being forgotten. Telehealth-based classes for physical activities have been experienced as helpful during the pandemic (Mousing et al., 2021; Madawala et al., 2023a; Swain et al., 2023).

## Women living with chronic obstructive pulmonary disease

As previous research shows, women living with COPD experience challenging symptoms, job loss, reduced social involvement, and disrupted familial connections. To manage everyday life, they face the necessity of creating coping strategies and action plans. Women have reported wishing for increased knowledge, more-supportive healthcare providers, and stronger social connections to carry out these strategies (O'Neill, 2002; Steindal et al., 2017). According to Stridsman (2013), female sex is a significant risk factor for fatigue while living with COPD and means living an everyday life controlled by fatigue. Meanwhile, Jonsdottir and Jonsdottir (2007) report that women with COPD experience being caught in a metaphorical spiderweb related to smoking relapse. Greater focus on the woman as an individual has been highlighted in supporting smoking cessation (Nyqvist et al., 2014). However, a simultaneous focus on both neurobiology and phenomenology of embodiment and affordances has provided new perspectives on smoking cessation among people with COPD (Klinke & Jonsdottir, 2014). Meanwhile, in addition to the above effects, women with COPD in high-income countries, including Sweden, face the negative impact of social stigma, which acts as a barrier to receiving quality healthcare; this affects their quality of life, health, and well-being (O'Neill 2002; Woo et al., 2021). Women with COPD are more affected by their disease than men, and this can lead to both a higher use of healthcare services and a struggle to obtain enough time with healthcare personnel (Jenkins et al., 2017; Martinez et al., 2012).



## Close relatives to people with long-term illness

Close relatives of people with COPD play important roles; they often provide the main practical, emotional, and social support for people with COPD during their everyday lives (Nakken et al., 2015; Ek et al., 2015). Living with a person who has a serious long-term illness – such as COPD at stages III or IV – often affects close relatives, forcing them to alter their everyday lives so that they can take on new and different responsibilities (cf. Öhman & Söderberg, 2004).

Close relatives of people with COPD may provide crucial support, but their role evolves as care needs increase. This shifting dynamic affects relationships; the belief that COPD is self-inflicted often further strains them (Lindqvist et al., 2013a; Lindqvist et al., 2013b; Sundh & Ekström, 2016; Bragadottir et al., 2018; Fusi-Schmidhauser et al., 2020). Close relatives also face challenges including isolation, caregiving fatigue, fear, and anxiety due to the unpredictability of COPD (Marques et al., 2015; Sundh & Ekström, 2016; Badr et al., 2017; Andersen et al., 2018; Yohannes et al., 2018; Siltanen et al., 2019; Sigurgeirsdottir et al., 2019). Such relatives also contend with emotional strain from intimacy loss (Jacome et al., 2014), which affects quality of life, well-being, and overall lifestyle (Stridsman et al., 2015a; Miravittles et al., 2015; Sundh & Ekström, 2016; Bagnasco et al., 2021; Yi et al., 2021). Close relatives who provide care have called for additional involvement in healthcare decisions and comprehensive information (Cruz et al., 2017).

## Healthcare encounters for people with long-term illness

Healthcare encounters are common interactions among healthcare personnel, people living with long-term illnesses, and close relatives of those who are ill (Holopainen et al., 2014). During these encounters, communication that involves mutual sharing, dialogue, conversation, and exchange of ideas, is fundamental to high-quality care (Fossum, 2019). A healthcare encounter can thus function as an opportunity for people with long-term illnesses to share their experiences, knowledge, and needs regarding their conditions (Holopainen et al., 2014). Communication is a core clinical skill, which constitutes verbal and non-verbal aspects in varying contextual and cultural settings (Attree, 2001). A positive relationship develops through mutual favourable relations, open communication, and awareness and trust that healthcare personnel are dependable. The nurse-patient relationship concludes to be a helping relationship (Allande-Cusó et al., 2022). Healthcare personnel bear a necessary responsibility to create these opportunities for positive relationships (cf. Holopainen et al., 2019; cf. Nygren-Zotterman et al., 2022). People with long-term illnesses have reported experiencing healthcare encounters as providing dignity when healthcare personnel have confirmed patients' experiences (Nygren-Zotterman et al., 2022).

In contrast to positive healthcare encounter experiences, negative healthcare encounters have been linked to lower satisfaction with quality of care and insufficient communication (Attree, 2001). When people struggle to obtain healthcare information, it tends to impair their ability to ask questions and participate in decisions regarding their treatment (Kourkouta & Papathanasiou, 2014). Moreover, people with smoking-related long-term illnesses, such as COPD, can be extra-

vulnerable to poor experiences in healthcare encounters, which can lead to stigma and to feelings of guilt and shame (Madawala, 2023b).

# Rationale for the doctoral thesis

The discipline of nursing science consists of two aspects: nursing and caring. The nursing aspect focuses primarily on nurses' areas of work, and stands for the 'what' of what nurses do. The caring aspect includes identifying needs and resources for people with health problems, and stands for the 'how' of nurses knowing how to use knowledge. Caring also has a humanistic meaning, centred on the relationship between people with health problems and healthcare personnel (cf. Arman et al., 2015; Karlsson & Pennbrandt, 2020).

The literature review demonstrates that the body of research about women with COPD at stages III or IV and their close relatives is sparse. Earlier research show that the majority of studies focus is on men or are a mix of both men and women. Therefore, this doctoral thesis focuses on women with COPD stage III or IV and highlight their everyday life and reflecting women's voices. Further, the review also reveals a lack of knowledge concerning the everyday lives of women living with severe COPD, including meanings of feeling well, meanings of healthcare encounters and the experiences of their close relatives. This doctoral thesis explores these areas, to provide possibilities for improving nursing and caring in ways that can improve meeting the needs, resources, and expectations of women with severe COPD and their close relatives. For nurses, it is important to have knowledge about ill people's needs, and resources to meet and design relevant nursing interventions (cf. Karlsson & Pennbrandt, 2020). Already Florence Nightingale (1859/1946) highlighted the needs for nurses to have knowledge about the illness experiences in order to develop individual nursing interventions for meeting the ill persons need. This is also a starting point for person-centred care, which means that nurses and other healthcare personnel listen to and try to understand the ill persons own narration (Ekman et al., 2011).

# Aim

The overall aim of this doctoral thesis was to explore, describe and generate knowledge about women's experiences of living with COPD stage III or IV and the experiences of their close relatives.

The following specific aims were formulated:

- Paper I      The aim of this study was to describe women's experiences of living with COPD stage III or IV.
- Paper II     The aim of this study was to elucidate meanings of feeling well for women with COPD stage III or IV.
- Paper III    The aim of this study was to elucidate meanings of healthcare encounters for women with COPD stage III or IV.
- Paper IV    The aim of this study was to explore and describe the experiences of close relatives of women with COPD stage III or IV.

# Method

## Context

This doctoral thesis has been conducted in a central Swedish region with 245,000 residents. Characterized as sparsely populated, this area comprises a blend of urban and rural zones, with nearly a third of its inhabitants residing in rural settings (Statistics Sweden, 2023). In this region, a total of three county hospitals serve a land area of 21 548 km<sup>2</sup>. The inland community hospital, part of the primary care services available, offers some inpatient services, emergency care, and some additional amenities.

The participants in this doctoral thesis comprised of: women with COPD at stages III or IV and considered as a unit, and their close relatives. Most of the women with COPD at stages III or IV lived at home and alone. Their residences were mostly flats, and a few women received homecare. Most of these women received care and support from the primary healthcare setting.

Both national and international guidelines apply in this setting for the care of people with COPD (National Board of Health and Welfare, 2020). In primary healthcare in the county of Västernorrland, there are some nurses working with people diagnosed with asthma/COPD, tobacco cessation and the majority of those nurses are educated in COPD. However, to date, far from all primary care health centers in the region are staffed with specialized nurses in COPD (County of Västernorrland, 2018).

# Naturalistic paradigm

A paradigm is a way of looking at natural phenomena, a worldview which encompasses a set of philosophical assumptions that guide the approach to inquiry (Polit & Beck, 2021). The naturalistic paradigm (also named the constructivistic paradigm) is founded on the belief that understanding the context of human behaviours is as necessary as the individual gaining such understanding (Lincoln & Guba, 1985). According to Lincoln and Guba (1985) reality is constructed and context-bound, meaning it changes in different contexts. The naturalistic paradigm examines the research question in its natural context, without intervention, to create and discover knowledge. This enables discovering knowledge from different realities preferably inductively with qualitative methods and a purposive sample. Through respectful relationships between the researcher and the participants, developed during interviews, a researcher can gain research data with depth and richness. This becomes the output from the interactions of the studies and is evident by people's statements and quotes (Lincoln & Guba, 1985).

In this real-world setting, the researcher acts as the tool of the inquiry, and strives for openness to whatever emerges. The naturalistic paradigm is based on humanism, including trustworthiness, which is closely linked to nursing science ontologies. Naturalistic inquiry does not seek absolute truth, as people's subjective experiences vary (Lincoln & Guba, 1985).

The naturalistic paradigm is also called the natural environment of the participants' world (Lincoln & Guba, 1985). In this doctoral thesis, the interviewer meets the people (women) in their homes (or by telephone) for interviews about women's experiences of living with COPD at stages III or IV and the experiences of their close relatives. These

interviews have been conducted via open-ended questions that were posed in a natural environment to women with COPD at stages III or IV, and to their close relatives, to obtain descriptions of their lived experiences.

Based on these assumptions this doctoral thesis has used two different methods (i.e., qualitative content analysis respectively phenomenological hermeneutical interpretation) for analysing the participants experiences. This choice was made in order to generate knowledge in line with the overall aim of this thesis.

## Design

A qualitative design has been selected to reach the aim of this thesis. Table 2 provides an overview of the study's aim, design, methods, participants, and data collection.



Table 2. *Overview of study aim, design, methods, participants, and data collection (I-IV)*

<b>Paper</b>	<b>Aim</b>	<b>Design</b>	<b>Method</b>	<b>Participants*</b>	<b>Data Collection* *</b>
<b>I</b>	The aim of this study was to describe women's experiences of living with COPD stage III or IV.	Qualitative	Qualitative content analysis	Fifteen women with COPD stage III or IV	Individual semi-structured interviews
<b>II</b>	The aim of this study was to elucidate meanings of feeling well for women with COPD stage III or IV.	Qualitative	Phenomenological hermeneutical interpretation	Fourteen women with COPD stage III or IV (seven women from Paper I)	Individual narrative interviews
<b>III</b>	The aim of this study was to elucidate meanings of healthcare encounters for women with COPD stage III or IV.	Qualitative	Phenomenological hermeneutical interpretation	Twelve women with COPD stage III or IV (two women from Paper no I and two women from Paper II)	Individual narrative interviews
<b>IV</b>	The aim of this study was to describe experiences as a close relative to women with COPD stage III or IV.	Qualitative	Qualitative content analysis	Nine close relatives to women with COPD stage III or IV	Individual semi-structured interviews

\* 30 different women, 9 close relatives \*\*50 interviews

In this doctoral thesis, sample size in the qualitative studies was based on the concept of information power from Malterud (2016). Malterud (2016) presents a model of information power to guide sample size. Information power is related to the aim of a study; this can be a broad aim, such as the ways in which people generally experience a specific phenomenon. A broad aim requires a larger sample size than a narrow one, such as studying a very specific or rare experience, which could in itself limit the number of participants available, to gain information power within the sample (narrow–broader). Sample specificity describes the experiences and knowledge of the participants included in a study: a variety not only of experiences and knowledge, but also of ages and types of condition. Experiences not previously described and purposive sampling enhance information power (dense or sparse) also see Table 3. Theory serves to synthesize existing knowledge and to extend the sources of knowledge beyond the empirical interview data, particularly regarding whether they elucidate a crucial theoretical element (applied or not). Dialogue is related to the quality of the interview; higher quality requires clear, strong communication, and thereby fewer participants. The skills of the interviewer, the articulation of the participants, the relationship between them, and pre-understanding, also compose (strong or weak) information power. Regarding analysis strategy, an exploratory cross-case analysis requires more participants to obtain an effective level of information power. In a study aiming at in-depth analysis, discourse and narratives (case or cross-case) from a few selected participants are suitable to obtain information power. Figure 1 illustrates this study's application of information power.

<b>Paper</b>	<b>I</b>	<b>II</b>	<b>III</b>	<b>IV</b>
Aim (narrow to broad)	To describe women's experiences of living with COPD stage III or IV <b>narrow</b>	To elucidate meanings of feeling well for women with chronic obstructive pulmonary disease stage III or IV <b>narrow</b>	To elucidate meanings of healthcare encounters for women with COPD stage III or IV <b>narrow</b>	To describe experiences as a close relative to women with COPD stage III or IV <b>narrow</b>
Sample specificity (dense to sparse)	Women with COPD stage III or IV > 18 y, Swedish speaking <b>dense</b>	Women with COPD stage III or IV > 18 y, Swedish speaking <b>dense</b>	Women with COPD stage III or IV > 18 y, Swedish speaking <b>dense</b>	Close relatives to women with COPD stage III or IV > 18 y, Swedish speaking <b>dense</b>
Theory (applied or not)	Eriksson, Toombs <b>applied</b>	Eriksson, Toombs, Carel <b>applied</b>	Buber, Carel <b>applied</b>	Buber, Bury, Toombs <b>applied</b>
Dialogue (strong or weak)	md= 60 min <b>strong</b>	md = 57 min <b>strong</b>	md = 63 min <b>strong</b>	md = 62 min <b>strong</b>
Analysis strategy (case or cross-case)	<b>cross-case</b>	<b>cross-case</b>	<b>cross-case</b>	<b>cross-case</b>

Figure 1. This study's model of information power, as inspired by Malterud (2016).

# Pre-understanding

Pre-understanding is based on the researcher's prior experiences with the research context and related traditions, which could be a resource, but may constrain understanding. This is true in striving for trustworthiness in this thesis and as in all qualitative research (cf. Graneheim et al., 2017). The researcher is the instrument, and it is crucial to clarify the researchers pre-understanding because of the critical importance of remaining open and continuously reflecting throughout the process of analysis (cf. Nyström & Dahlberg, 2001).

In this doctoral thesis, I have made effort in all four studies to follow the consideration called 'bridling', as described by Dahlberg et al. (2008); this entails maintaining awareness of how my prior experiences and education could affect the findings. I have moved between subjectivity and objectivity, to see that many possible understandings are present. I have reflected and considered my pre-understanding, as it could pose an obstacle to open-mindedness, to avoid taking things for granted during interview situations (cf. Dahlberg et al., 2008; Nyström & Dahlberg, 2001). I have actively recognized and set aside my personal beliefs. My perspective is influenced by my extensive experience as a registered nurse, working with patients with chronic illnesses. In striving for an open mind, I have conducted continuous dialogues with my supervisors and peers to enrich awareness regarding these assumptions. Reflexivity means acknowledging these assumptions (cf. Dahlberg et al., 2008; Polit & Beck, 2021).

# Participants and procedure

Table 3. *An overview of the participants (I-IV).*

Characteristics	Paper I	Paper II	Paper III	Paper IV
Age, md (min-max)	75 y (50-84)	69 y (52-86)	57 y (45-85)	57 y (45-85)
Participants, n	Women 15	Women 14	Women 12	Close relatives 9 Husbands 3 Cohabitant 1 Daughters 3 Friends female 2
Education level, n				
- Secondary school	4	3	3	6
- High school	7	7	5	3
- Higher education	4	2	4	0
Retired, n	14	12	9	4
Part time working, n	1	1	1	5
Living alone in flat, n	9	5	8	
Living with husband or spouse, n	5	9	4	4
Living in retirement home, n	1	0	0	
Home care, n	4	4	na	
Ex-smoker, n	11	na	na	
Never smokers, n	2	2	2	
Years living with COPD, md (min-max)	10 (2-30)	16 (2-25)	14 (5-21)	
Oxygen at home, n	7	7	6	

\*na= not applicable

## **Paper I**

### **Participants**

A purposive sample of 15 women diagnosed with COPD at either stage III or IV participated in this study. The inclusion criteria for participation were women, aged 18 years or older, diagnosed with COPD stage III or IV, with the ability to speak and understand Swedish. Two had alpha-1 antitrypsin deficiency. Seven received home oxygen treatments. Among the 15 participants, the median age was 75 years old (in a range from 50–84). The women had been diagnosed with COPD in median 12 years (in a range from 2–30 years). Participants' educational backgrounds varied: four had completed secondary education, seven had completed high school, and four had some higher education. Fourteen were retired, either on time or early; one worked part-time. Most women lived alone, while five were married or cohabiting. Residences were mostly flats; one woman lived in a nursing home.

### **Procedure**

The head of the Department of Pulmonary Medicine at a hospital in the region gave permission to recruit the participants for this study, and agreed to assist with recruiting. The healthcare personnel involved in the participants' care received information about the studies in this doctoral thesis at staff meetings prior to the start of the project. Additional meetings with the department secretary were held to instruct staff regarding the inclusion criteria and distribution of the invitation letters. The invitation letter packets contained information about the studies, an informed consent form, and a reply form.

A secretary at the Department of Pulmonary Medicine at the hospital distributed 50 invitation letter packets, based on the inclusion criteria. The 15 women who gave their permission to participate sent their reply and informed consent forms to Mid Sweden University. The women were then contacted by telephone to arrange the interviews. Before commencing the interviews, each participant received verbal information about the study, and was provided time for questions. It was made sure that each participant had a copy of their written informed consent. They were given the opportunity to choose the time they preferred and participants could split sessions and was offered pauses if needed due to their severe illness and breathlessness.

## **Paper II**

### **Participants**

A purposive sample of 14 women diagnosed with COPD at stage III or IV participated in this study. The inclusion criteria for participation were women, aged 18 years or older, diagnosed with COPD at stage III or IV, with the ability to speak and understand Swedish. Among the 14 participants, the median age was 69 years old (in a range from 52–86). The women had been diagnosed with COPD in median 16 years (in range from 2–25 years). Two had alpha-1 antitrypsin deficiency; seven received oxygen treatments. Participants' educational backgrounds varied: three had completed secondary school, seven had finished high school, and two had some higher education. Twelve were retired, on time or early; one woman worked part-time; and one was unemployed. Five lived alone, while nine were married or cohabiting. Most participants lived in flats, while some lived in houses. Four of the women used home-care services.

## Procedure

The head of the Department of Pulmonary Medicine at a hospital in the region gave permission to recruit participants for this study, and agreed to assist with recruitment. The healthcare personnel involved in the participants' care received information about the studies in this doctoral thesis at staff meetings prior to the start of the project. Additional meetings with the coordinator were held to instruct staff regarding the inclusion criteria and distribution of the invitation letter packets. The invitation letter packets contained information about the studies, an informed consent form, and a reply form.

A coordinator at the Department of Pulmonary Medicine distributed 50 invitation letter packets based on the inclusion criteria. In addition to those invitations, women who had participated in study I were invited to study II. The 14 women who agreed to participate sent their reply and informed consent forms to Mid Sweden University. The women were then contacted by telephone to arrange the interviews. Before commencing the interviews, each participant received verbal information about the study, and was provided time for questions. It was made sure that each participant had a copy of their written informed consent. Each was given the opportunity to choose the time they preferred and participants could split sessions and was offered pauses if needed due to their severe illness and breathlessness.



## **Paper III**

### **Participants**

A purposive sample of 12 women diagnosed with COPD at stage III or IV participated in this study. The inclusion criteria for participation were women, aged 18 years or older, diagnosed with COPD at stage III or IV, with the ability to speak and understand Swedish. Among the 12 participants, the median age was 71 years old (in a range from 52–86). The women had been diagnosed with COPD in median 14 years (in a range from 5–21 years). Two had alpha-1 antitrypsin deficiency. Six women received oxygen treatments. Participants' educational backgrounds varied: three had completed secondary school, five had finished high school, and four had some higher education. Nine participants were retired; one worked part-time; and one was unemployed; employment information for one participant was absent. Residences were mostly flats. Eight of the participants lived alone, four were married or lived with a partner, and all lived at home. It was made sure that each participant had a copy of their written informed consent. Participants could split sessions if needed due to their severe illness and breathlessness.

## Procedure

The head of the Department of Pulmonary Medicine at a hospital in the region gave permission to recruit participants for this study, and agreed to assist with recruitment. The healthcare personnel involved in participants' care received information about the studies in this doctoral thesis at staff meetings prior to the start of the project. Additional meetings with the coordinator were held to instruct staff regarding the inclusion criteria and distribution of the invitation letter packets. The invitation letter packets contained information about the studies, an informed consent form, and a reply form.

A coordinator at the Department of Pulmonary Medicine distributed 38 invitation letters based on the inclusion criteria. In addition to those invitations, women who had participated in studies I and II were invited to Study III. The packets included information about the study, an informed consent form, and a reply form. The 12 women who agreed to participate sent their reply and informed consent forms to Mid Sweden University. The women were then contacted by telephone to arrange the interviews. Before commencing the interviews, each participant received verbal information about the study, and was provided time for questions. It was made sure that each participant had a copy of their written informed consent. Each was given the opportunity to choose the time they preferred and participants could split sessions and were offered pauses if needed due to their severe illness and breathlessness.

## **Paper IV**

### **Participants**

A purposive sample of nine close relatives of women diagnosed with COPD at stage III or IV participated in this study. The inclusion criteria for the participants were close relatives of women diagnosed with COPD at stage III or IV, aged 18 years or older and with the ability to speak and understand Swedish. Participants consisted of five women and four men, with a median age of 57 (in a range from 45–85 years). Among the participants, educational backgrounds varied: six had finished secondary school, and three had some higher education. Five worked, and four were retired. Four lived together with a woman who had COPD. None were informal caregivers.

### **Procedure**

The head of the Department of Pulmonary Medicine at a hospital in the region gave permission to recruit participants for this study. For this study, close relatives were invited to participate by the 15 women who participated in Study I. The women with COPD at stages III or IV identified prospective participants whom they considered to be their close relatives. The women administered invitation letters to their close relatives about the study. For purposes of this doctoral thesis, 'close relative' refers to a person identified by women with COPD at stage III or IV, and may be a spouse or/partner, sibling, or child, but might also be a friend or a neighbor. The nine close relatives who consented to participate sent their reply and informed consent forms to Mid Sweden University. The participating close relatives were then contacted by telephone to arrange the interviews. Before commencing the interviews, each participant received verbal information about the study, and was provided time for questions. It was made sure that each participant had a copy of their written informed consent.

# Data collection methods

In order to reach the aim of the present thesis both individual semi-structured interviews (I, IV), and narrative interviews were used (II, III).

## **Individual qualitative interviews (I, IV)**

Individual semi-structured interviews were conducted with women who had COPD stage III or IV (I) and their close relatives (IV). The aim of data collection via these interviews was to describe the participants' everyday lives and experiences (cf. Kvale & Brinkman, 2014).

## **Paper I**

The individual semi-structured interviews with fifteen women who had COPD stage III or IV were conducted by telephone due to COVID-19 restrictions. An interview guide was used and prior to the participant interviews, the guide was tested in a pilot interview (cf. Kallio et al., 2016). The interviews with women who had COPD focused on their experiences of living with COPD; the women were asked to describe their experiences of their everyday lives with COPD. Follow-up questions and prompts included, "Tell me more about that", and "Could you give me an example please?" Each interview lasted from 32–118 min (md = 60 min), and was recorded and transcribed verbatim. The interviews were conducted from March–May 2020. After the interviews, participants were encouraged to contact the interviewer with any questions.

## **Paper IV**

In this doctoral thesis, close relative refers to a person identified by the women with COPD stage III or IV, and may be a spouse or partner, sibling, or child, but could also be a friend or neighbour (cf. Blanck et al., 2021). The individual semi-structured interviews with nine close relatives focused on their experiences of being a close relative of a woman with COPD stage III or IV. An interview guide was used, which was tested beforehand in a pilot interview (cf. Kallio et al., 2016). Each close relatives was asked to speak about their everyday life as a close relative of a woman who had COPD stage III or IV. When clarification was needed, follow-up questions were asked, including “Can you tell me more about that?” and “Could you give me an example?” Each interview lasted from 39–76 min (md = 62 min), and was recorded and transcribed verbatim. Interviews were conducted from March–May 2020. After the interviews, close relatives were encouraged to contact the interviewer with any questions.

### **Narrative interviews (II, III)**

Narrative interviews (Mishler, 1986) were conducted with women who had COPD stage III or IV. In a narrative interview, the researcher encourages participants to freely express their lived experiences with a specific topic within the research aim (Mishler, 1986). According to Ricoeur (2014), to retell, or narrate, means to bring the past into the present, and generate possibilities to form the future.

## **Paper II**

Fourteen narrative interviews with women who had COPD stage III or IV were conducted by telephone. Data were collected via these individual interviews, regarding their lived experiences of feeling well. The interviews opened by asking the women to narrate their experiences of feeling well, and their experiences of feeling less well. Probing and encouraging questions were also asked, such as “What do you mean?”; “How did this make you feel?”; “What happened next?”; and “Can you tell me more about that?” The interviews lasted from 30–70 min (md = 57), and were audio recorded and transcribed verbatim. The interviews were conducted from March–October 2022. After the interviews, participants were encouraged to contact the interviewer with any questions.

## **Paper III**

Twelve narrative interviews with women who had COPD stage III or IV were conducted by telephone or in person; two of the women chose in-person interviews. The interviews commenced by asking the women with COPD stage III or IV to narrate their experiences of healthcare encounters. Probing and encouraging questions were also asked, such as “What do you mean?”; “What happened next?”; “How did this make you feel?”; and “Can you tell me more?” The interviews lasted from 15–110 min (md = 63), and were audio recorded and transcribed verbatim. The interviews were conducted from March–October 2022. After the interviews, participants were encouraged to contact the interviewer with any questions.

# Data analysis methods

In this thesis, the aim of each study has guided the choices of data analysis methods.

## **Qualitative content analysis (I, IV)**

The interview texts were analysed via the qualitative content analysis approach described by Graneheim and Lundman (2004). Qualitative content analysis is a very common method for analysing qualitative data. The method for analysing qualitative data focuses on content, and variation as means of developing an extended knowledge of human health and illness (Graneheim & Lundman, 2004). Qualitative content analysis can be both descriptive and interpretive, and can offer both depth and meaning (Lindgren et al., 2020).

The inductive approach used in studies I and IV involved a text-driven search for patterns. The data analysis process began with reading and re-reading the interview text to obtain a sense of the content of women's experiences of living with COPD stage III or IV, in study I and describe the experiences as a close relative to women with COPD stage III or IV, in study IV. In the next step, units of meaning were identified, condensed, and coded. The condensed and coded units were then sorted into categories based on similarities and differences. Categories in this context have been described as groups of content that share commonality (cf. Graneheim & Lundman, 2004). After comparing categories, recurring threads of meaning were identified, which led to the identification of themes. The underlying meanings running through these descriptive categories, interpret the latent content, and formulate sub-themes and/or themes (Graneheim & Lundman, 2004). According to Lindgren et al., (2020) developing

themes does not always need prior categorization. With rich data and expressive codes, you could move from codes to sub-themes and, eventually, abstract and interpret themes. The analysis was validated by refining themes with multiple categories through transcript review. The analysis was performed in collaboration with my supervisors.

### **Phenomenological hermeneutical interpretation (II, III)**

The phenomenological hermeneutical method used in this thesis has been developed by Lindseth and Norberg (2004) for nursing research. The development of the method is inspired by the theory of interpretation presented by the French philosopher Ricoeur (1976). According to Ricoeur (1976), language provides opportunities for shared understanding regarding the meanings of experiences. The phenomenological hermeneutical method strives to deepen understanding of the phenomena under study (cf. Lindseth & Norberg, 2004). Phenomenological hermeneutical interpretation is suitable to exploring meanings of people's lived experience. In this doctoral thesis lived experiences has been elucidated in study II meanings of feeling well for women with COPD stage III or IV and meanings of healthcare encounters for women with COPD stage III or IV, in study III. Phenomenology, has a focus on the descriptive and hermeneutics, describes the interpretation of the life world. The lifeworld is the world we humans live in, and that we take for granted without reflection and reveals the insider's perspective (Lindseth & Norberg, 2004).

The phenomenological hermeneutical interpretation approach consists of three interrelated phases. The interpretation process begins with a naïve understanding, aimed at obtaining a sense of the immediate meaning of the text as a whole. This is followed by a structural analysis, the goal of which is to explain what the texts say (Lindseth & Norberg, 2021). The last phase is known as comprehensive understanding; the



goal of this phase is to deepen the understanding of what the text as a whole indicates.

In studies II and III, data analysis began with a naïve understanding, meaning that the interview texts were read several times to gain a sense of the whole. This was followed by thematic structural analysis, in which the texts were read and divided into units of meaning, such as a sentence or paragraph that communicates a single meaning. The units of meaning were then condensed and subsumed into subthemes and themes. During the last phase, comprehensive understanding, the text was again interpreted as a whole, keeping in mind the author's pre-understanding, the author's naïve understanding, the results of the structural analysis, and the literature review (cf. Lindseth & Norberg, 2004). The relevant literature was used to provide insight into the participants' lived experiences of the phenomena under study. The most likely and probable interpretation was then determined (Lindseth & Norberg, 2021), based on the mutual understanding of all three authors.

# Ethical considerations

In accordance with the laws of Sweden, the act (2003:460) concerning the ethical review of research involving humans has been followed: ethical approval was obtained from the Swedish Ethical Review Authority (No. 2020-00085, 2022-00369-02) before commencing the studies in this doctoral thesis. This doctoral thesis were conducted in agreement with the declaration of Helsinki (World Medical Association, 2018) which includes aspects for safeguarding human beings.

To follow a moral, legal and ethical responsibility, prior to the start of the interviews, the participants were provided with accurate information about informed consent, confidentiality, their rights to voluntarily participate, and anonymity in the presentation of the findings. Moreover, participants were provided with time for questions before and after each interview. To protect confidentiality, no information from the participants, or collected data, will be accessible to anyone other than the researcher (Polit & Beck, 2021). To follow general data protection regulation (GDPR) (2016:679) the interview material has been handled according to the law. All digital material has been stored safely and beyond outsiders' reach in accordance with the act of archives (1990:782).

According to the Swedish Research Council (2017) the participants health and well-being, their rights and the respect of all humans should precede any aim of researchers, society, or other stakeholders. This means to be attentive to other interests, such as the economical or personal interests of research results and the code of conduct is important (cf. All European Academies ALLEA, 2017). In this doctoral thesis, the knowledge may be used to enhance everyday life of women with COPD stage III or IV and their close relatives. In case of any

emotional reaction caused by the conducted interviews at a later stage, the participants were given contact information about proceedings. To this date, no one has requested this support or has reported any inconvenience. I was trying to have a critical stance about power balance, and possible oppression in the interview situation with the participants. All participants were informed of the possibility of withdrawal at any time and without any explanation. There was no dependent relationship between the participants and researchers in this thesis.

# Findings

The overall aim of this doctoral thesis was to explore, describe and generate knowledge about women's experiences of living with COPD stage III or IV and the experiences of their close relatives. The findings show that women with COPD stage III or IV experienced loss of abilities in managing everyday life activities due to their unpredictable ever-present breathlessness. Support from family, healthcare professionals, and digital media were crucial (I). For women with COPD, feeling well meant aligning their daily activities to their breathing rhythm. Participants reported using physical aids, their own expert knowledge, and support from close relatives to maintain independence and to slow down the illness progression. Finding joy in everyday life contributed to feeling well (II). In healthcare encounters, women with COPD valued having sufficient time to express their needs. Feeling neglected led to not feeling confirmed (III). Close relatives to women with COPD expressed providing women with practical and emotional support, often disrupting their own lives. They had difficulties in understanding the woman's ill health and tailored information could enhance their support (IV).

The findings from the four papers are presented separately. In Table 4 provides an overview of themes and categories presented for studies I and IV. Table 5 is an overview of themes and subthemes presented for studies II and III.

Table 4. *Overview of themes and categories for studies (I, IV), analysed with qualitative content analysis*

<b>Paper</b>	<b>Themes</b>	<b>Categories</b>
<b>I</b>	Stabilizing an ever-present breathlessness by restoring strength	Managing a restricted everyday life as an expert of their illness Being afraid of contracting infections leading to suffocation and suffering Importance of continuous help and support from significant others and digital media
<b>IV</b>	Difficulty in understanding the woman's ill health Giving practical and emotional support Experiencing stress and uncertainty related to a woman's ill health Lacking tailored information about COPD	

Table 5. *Overview of themes and subthemes for studies (II, III), analysed with phenomenological hermeneutical interpretation.*

<b>Paper</b>	<b>Themes</b>	<b>Subthemes</b>
<b>II</b>	Striving for moments of feeling well despite being trapped in breathlessness	Acting in rhythm with breathing Taking care of oneself Taking advantage of better moments Being in togetherness in everyday life
<b>III</b>	Being met as a person and not as a diagnosis	Getting sufficient time and feeling involved in care Fulfilment of personal needs Experiencing disrespect and injustice

## Paper I: Living with an ever-present breathlessness: Women's experiences of living with chronic obstructive pulmonary disease stage III or IV

The study presented in this paper aimed to describe women's experiences of living with COPD stage III or IV. Women with COPD were restricted by an unpredictable and ever-present breathlessness in all aspects of their daily lives. To manage this situation, they adapted based on their energy levels. This required planning and focused knowledge regarding their breathing and bodies. The women feared infections, which caused them suffering. This fear led to isolation, and using digital media was a way to ease this isolation. Significant others were important to them in managing everyday life (i.e., the theme *Stabilizing an ever-present breathlessness by restoring strength*, with the three categories: *Managing a restricted everyday life as an expert of their illness*; *Being afraid of contracting infections leading to suffocation and suffering*; and *Importance of continuous help and support from significant others and digital media*).

The theme *Managing a restricted everyday life as an expert of their illness* refers to women with COPD scheduled their activities and used their knowledge of their illness to handle everyday tasks. The women experienced mood alterations and grief regarding the loss of abilities. When their illnesses worsened, they used breathing techniques and considered medications. Physical aids were invaluable to preventing isolation and enabled participation in activities. For the women with COPD, limited energy often led to isolation at home. Maintaining a positive outlook and focusing on living in the present helped them to manage and adapt.

The category *Being afraid of contracting infections leading to suffocation and suffering* refers to the women with COPD had expressed fear of infections. They believed a COVID-19 infection would be fatal, and given their ever-present breathlessness, they wished to avoid suffering in a life-threatening situation. Although the women had had previous thoughts about the possibility of death, the pandemic made this conversation urgent. They reported integrating social distancing and isolation, and avoided home care, due to pandemic-related fears.

The category *Importance of continuous help and support from significant others and digital media* refers to the women with COPD expressed the importance of their relationships with close relatives and healthcare personnel for support. They also found online communities valuable for sharing advice. Companionship, whether in-person or digital, was essential, especially during the COVID-19 pandemic. The women also relied on close relatives for help with everyday tasks. In healthcare interactions, most of the women had positive experiences with in-patient healthcare personnel, although a few had encountered negative interactions. The women expressed that having COPD generated a feeling of shame. They called for increased continuity in their healthcare relationships; they also called for increased continuity and personalized, tailored healthcare.

## Paper II: Striving for moments of easier breathing despite being trapped in breathlessness: Meanings of feeling well for women with chronic obstructive pulmonary disease stage III or IV

The study presented in this paper aimed to elucidate meanings of feeling well for women with COPD stage III or IV. The findings showed that for women with COPD, feeling well meant that they stroved and planned for moments of easier breathing despite being trapped in breathlessness. It was important to spend time in nature, which helped them to feel less trapped. They experienced feeling well via support from others, which inspired feelings of independence, worthiness, and togetherness (i.e., the theme *Striving for moments of feeling well despite being trapped in breathlessness*, with four subthemes: *Acting in rhythm with breathing*; *Taking care of oneself*; *Taking advantage of better moments*; and *Being in togetherness in everyday life*).

The subtheme *Acting in rhythm with breathing* refers to women with COPD planned their activities in rhythm with their breathing; in combination with a positive attitude, this meant moments of feeling well for them. In addition, being outdoors surrounded by nature had brought them feelings of being alive. The opposite situation, being unable to do what they wanted due to breathlessness, meant feelings of frustration.

The subtheme, *Taking care of oneself*, refers to the ability of the women with COPD to how they managed their everyday lives in order to feel well; they accomplished this by relying on various types of support. Important support types included physical aids and close relatives who acted as extensions of the women's bodies. Further elements of support included knowledge of how to perform activities in order to slow down the illness progression. To prepare for their death also



seemed to lead to feeling well, in the sense of increased contentment derived from knowledge and discussions with close relatives, and healthcare personnel.

The subtheme *Taking advantage of better moments* refers to that women with COPD stage III or IV seemed to live in the present despite their limiting breathlessness, even as they felt time was running out. Reflecting, enjoying being alive, and being able to perform meaningful tasks meant feeling well. Women wanted to engage in activities healthy people tend to take for granted, and have a bit of fun.

The subtheme *Being in togetherness in everyday life* refers to that women with COPD stage III or IV feeling well and worthy when they were able to maintain contact with family and friends, via any kind of communication including face-to-face meetings. In contrast, when they felt trapped in breathlessness, they tended to feel a sense of dependence and an inability to contribute to family, the economy, and society.

### Paper III: Being met as a person and not as a diagnosis – meanings of healthcare encounters for women with chronic obstructive pulmonary disease stage III or IV

The study presented in this paper aimed to elucidate meanings of healthcare encounters for women with COPD stage III or IV. The findings showed that meanings of healthcare encounters for women with COPD involved feeling confirmed or disconfirmed (i.e., The theme *Being met as a person and not as a diagnosis*, with three subthemes: *Getting sufficient time and feeling involved in care*; *Fulfilment of personal needs*; and *Experiencing disrespect and injustice*).

The subtheme *Getting sufficient time and feeling involved in care* refers to healthcare encounters were characterized by enough time for women with COPD stage III or IV to describe their needs. When women with COPD were in dialogue with healthcare personnel, they felt better able to describe their needs. They emphasized the significance of such dialogues within their healthcare encounters; when sufficient time was available, women felt they were involved in their own care and were taken seriously.

The subtheme *Fulfilment of personal needs* refers to women with COPD expected to receive clear, customized information and explanations of ways to manage their illness. For the women with COPD, prepared prescriptions meant increased independence. Continuity of care meant their further personal needs were being fulfilled, enabling them to feel comfortable and relaxed in healthcare encounters.

The subtheme *Experiencing disrespect and injustice* refers to the situation when women with COPD stage III or IV felt unseen as whole person, they felt ignored and not prioritized. Women reported that negative interactions in meeting healthcare personnel generated a feeling of stupidity for having smoked, which contributed to healthcare personnel seemed reluctant to share advice and to discuss women's treatment and symptoms. The women reported a strong sense that not being taken seriously when they were in need of help caused them to avoid seeking care. In addition, experiences in rural areas of feeling restricted in care choices and limited delivery of care generated a sense of injustice.

## Paper IV: The experiences of close relatives to women with chronic obstructive pulmonary disease stages III or IV: A qualitative study

The study presented in this paper aimed to explore and describe experiences of close relatives of women with COPD stage III or IV. Findings show that close relatives experienced stress and uncertainty, that were unpredictable in their everyday lives. They supported the women with COPD both practically and emotionally, and reported a desire for tailored information about COPD. Close relatives experienced difficulties in fully understanding the women's ill health; for themselves, breathing was something close relatives took for granted (i.e., the four themes: *Difficulty in understanding the woman's ill health*; *Giving practical and emotional support*; *Experiencing stress and uncertainty related to the woman's ill health*; and *Lacking tailored information about COPD*).

The theme *Difficulty in understanding the woman's ill health* refers to the need among close relatives of women with COPD stage III or IV needed to obtain help to better understand the women's ill health and the consequences of the illness. Over the course of the illness, mutual activities had changed. Although close relatives had become used to the ever-present breathlessness in the women with COPD, they continued to attempt to create new opportunities and shared the everyday difficulties.

The theme *Giving practical and emotional support* refers to close relatives described giving practical and emotional support in everyday life to women with COPD. This sometimes affected the close relatives' own everyday lives. The COVID-19 pandemic, for example, forced them to avoid infecting the women while continuing to provide safe support via digital media or smartphones.

The theme *Experiencing stress and uncertainty related to the woman's ill health* refers to close relatives' experience of stress within unpredictable everyday lives. Ongoing worries regarding the progression of the women's illness accompanied feelings of hopelessness, and a sense of walking on eggshells to protect the women with COPD. An additional challenge related to lack of time, which raised feelings of guilt for close relatives.

The theme *Lacking tailored information about COPD*, refers to close relatives called for a platform where they could exchange information and ask questions about the illness, its course, and its complications. Close relatives expressed that receiving tailored information could increase their knowledge and ability to support the women with COPD.

## Discussion

The overall aim of this doctoral thesis is to explore, describe and generate knowledge about women's experiences of living with COPD stages III or IV, and the experiences of their close relatives. The findings in this thesis will be discussed in the light of the theory of the suffering human being presented by Eriksson (2006; 2018), in which the opposite of health is not illness but suffering. Suffering is a part of health, and health is compatible with enduring suffering; a person who suffers can experience health at the same time (Eriksson, 2006; 2018). Women living with COPD stages III or IV, as well as their close relatives, show many faces of suffering as human beings, but also experience moments of health. The women's experiences of living with COPD stages III or IV can be seen as suffering of life, suffering of illness, and suffering of care. When it comes to the experiences of their close relatives it seems like close relatives experience suffering of life and suffering of care (Eriksson, 2006; 2018).

Suffering of life describes the suffering a person experience in relation to their changed life. When a person falls ill, their entire life can be turned upside down, which can add burden to their previous experience of life. Suffering of life is closely linked to a person's dignity, achievements, and ability to live up to their different roles. Suffering of illness can be linked to the consequences of people's ill health, illness, or related treatment, and include their bodies' capacity to function, or functions being impaired or gone. Suffering of care, occurs when a person's dignity is violated in healthcare, for example in situations where a person is not believed or taken seriously. Lack of care, or of being neglected during care, are forms of suffering of care. Moreover, different kinds of treatments can themselves cause unnecessary suffering (Eriksson, 2018).

The findings are further related to the meaning of illness presented by Toombs (1992). According to Toombs (1992) each person has their own understanding of their illness-related suffering. This understanding includes both a person's experiences of their illness, and the meaning the person gives to those experiences. When a person is healthy, the body is present by being experienced as absent, but when a person becomes ill, this changes. In addition, the findings are related to the phenomenology of illness presented by Carel (2016). Carel (2016) focuses on the phenomenology of the lived experiences of serious long-term illness and of well-being within illness. According to Carel (2016), the phenomenon of breathlessness is the understanding of breathing, which is what people normally take for granted, and is an extreme experience of breathing. Hence, the findings of this doctoral thesis will also be related to prior research.

Women with COPD stage III or IV felt trapped in their breathlessness and often needed help and support. Consequently, this made the women feel dependent, and unable to schedule their everyday lives (I, II). Due to their severe illness, they had faced many losses; including the sense of being able to care for others, and as worthy, active people of society contributing to the larger economy and to their families (II). This can be seen as suffering of life which means that a person's obvious life situation changes in terms of what they have been used to. A threat to a person's entire existence which can include being unable to fulfil social assignments can be seen as an expression of suffering of life (Eriksson, 2006; 2018). According to Carel (2016) breathlessness generate such feelings being trapped in a web of uncertainty, bodily doubt, practical obstacles, loneliness, and fear. Bury (1982) states that for ill people, the taken-for-granted world of everyday life becomes burdened by conscious actions. Disruption of friendships and

community involvement affects social interaction and restricts the ill person's familiar surroundings. This agrees with Van der Meide et al. (2020) who show that everyday life of people with COPD was dominated by concerns for their own body and vigilant avoidance of acute breathlessness and was experienced as being metaphorically trapped in their lungs while fighting a losing battle.

The women with COPD expressed fearing all kinds of infections, and they had attempted to avoid potential suffering through self-isolation, especially during the COVID-19 pandemic (I). Eriksson (2018) states that suffering of life means living with fear and despair, along with the fighting will to be alive. Women with COPD live with both an ever-present breathlessness that affects everyday life, and the fear of infections (I). This is in line with what Carel (2016) describes; the deepest fear is the one of suffocation. This inability to breathe feels like the chest is about to explode.

Women with COPD stages III or IV experienced that living with a serious long-term illness made them think of their deaths, caused them to consider making preparations for both death and life, and brought them feelings of reconciliation (II). People living with COPD have reported the desire to discuss difficult issues with healthcare personnel, without worrying their close relatives (Molzahn et al., 2021; Skär et al., 2023). Eriksson (2006; 2018) describes that living with the knowledge that you are going to die, but not knowing when, is coherent with suffering of life. Preparing for death, while simultaneously preserving autonomy, for people with a severe long-term illness could be enabled by mutual decision-making (Toombs, 1992); in this doctoral thesis, the women with COPD wanted to talk with their close relatives and healthcare personnel about preparations for their death (II). Carel (2016) describes illness as a state of being towards death; it can limit



everyday life. Moreover, health is present in death, and both life and death are closely linked.

The close relatives experienced difficulties in understanding the women's ill-health. They used digital communications channels to support the women with COPD during the COVID-19 pandemic. In addition, the close relatives asked for increased information about COPD, believing tailored information could enhance their support for the women with COPD (IV). According to Eriksson (2006; 2018) suffering of life involves a person's life situation changing not only for themselves, but also for their family. It is no longer possible to take for granted the families' everyday lives related to the women's illnesses (cf. Toombs, 1992). These findings align with Zotterman et al. (2018), who reported that close relatives of people with long-term illnesses felt comfort, confidence, and a sense of inclusion when provided information about the care of the ill person.

Women with COPD stages III or IV live with an unpredictable, ever-present breathlessness that impacts every aspect of their lives and beings (I). This can be seen as an expression of what Eriksson (2006; 2018) describes as suffering of illness, meaning that illness and treatment captures the focus of the ill person's everyday life. Carel (2016) describes the phenomenon of breathlessness as an overpowering sensation to which humans are deeply sensitive, which can be invisible to others.

Women with COPD were hindered from performing actions they wanted to do as they felt losses of abilities; this generated feelings of frustration as their illness gradually got worse. This affected women with COPD's independence (I, II). Living in a shrinking world, with increasing constraints and loss of abilities, is in line with what Carel

(2016) means when describing inability becoming a way of being. The illness represents things lost, gone, and given up on. According to Toombs (1992), illness is characterized as a way of being that incorporates loss of control, loss of freedom to act, and loss of the familiar world. Things taken for granted in everyday life are disrupted by the illness. Furthermore, the unpredictability of the ever-present breathlessness among women with COPD could be seen as what Carel (2016) presents as bodily doubt. The ill person experiences despair, anxiety, depression, and a lost hope due to their breathlessness. Bolton et al. (2022) show feelings of frustration are common, as people with severe COPD can no longer do neither their everyday activities nor their everyday chores.

Women with COPD expressed the importance of relations and connections in togetherness with family and friends (II). In parallel, the women described feeling well when they were able to keep contact with family and friends, using all kinds of communication tools (I, II). Eriksson (2006; 2018) states that to share life with someone else means togetherness, and provides something people can have in common during their everyday lives despite their suffering of illness. Togetherness and experiencing self-worth are of fundamental importance to health. These can be seen as expressions of health and contribute to alleviation of suffering (Eriksson, 1992). According to Carel (2016), the adaptation process includes the insider perspective: the experience of the ill person. Hence, the participating women with COPD expressed feeling well from an insider's perspective highlighting the importance of togetherness.

Women with COPD reported stabilizing their ever-present breathlessness by restoring strength and thinking positively. To preserve their energy was a way to endure (I, II). According to Eriksson (2018), suffering and health are indispensable to each other, and health

is compatible with enduring suffering. Carel (2021) shows that times when a person's breathing is in harmony may be interpreted as an experience of feeling well, despite living with a serious illness. According to Asp (2015), preserving energy by resting implies a sense of harmony among people with different kinds of long-term illnesses.

Women with COPD view themselves as experts of their own illness (I). They planned and acted in rhythm with their breathing, and used physical aids and available resources for support (II, IV). According to Carel (2012), bodily limitations can be reduced by physical aids when those aids are integrated as extensions of the body. Steindahl et al. (2017) claim that women with COPD experience a good life with adaptations, such as practicing slow and calm movements to prevent breathlessness. Practical and emotional support from close relatives included acting as extensions of the women's bodies, which increased the women's ability to take care of themselves and thereby feeling well (II, IV). Carel (2016) states that using conscious effort and learning how to live well with illness comprise a possibility for achieving well-being. In the current research project, close relatives who acted as extensions of the women's bodies needed a detailed understanding of how to best support them (II, IV).

Close relatives of the women with COPD expressed that they were used to the women's ever-present breathlessness. They reported living stressful everyday lives, accompanied by feelings of guilt when unable to be present for support (IV). Eriksson (2006; 2018) states that people's feelings of guilt represent their suffering. Rehnsfeldt and Eriksson (2004) describe a risk for ill people (i.e., the women with COPD) of becoming stuck in sustainable suffering if not provided sufficient attentiveness. This is in line with Öhman and Söderberg (2004), who state that close relatives felt an unexpressed demand of always being accessible to the severely ill person.

Women with COPD stages III or IV experienced feeling unprioritized during healthcare encounters, and sometimes even felt ignored concerning their breathlessness by healthcare personnel. In these situations, the women felt seen as diagnoses, rather than as a person (III). This can be seen as what Eriksson (2006; 2018) presents as suffering of care, an unnecessary suffering that occurs when the dimension of caring is absent. In the healing relationship between the ill person and healthcare personnel, attention should focus on the experience of the person who is ill, rather than on the disease process (Toombs, 1992). Not being seen as a person (i.e., feeling ignored) could be seen as an expression of disconfirmation, which Buber (1937; 2000) presents as an “I-It” relationship, in which the other person is experienced as an object. Further, if nurses and other healthcare personnel were aware of their ethical responsibilities which was evident in their choices of actions and interventions to do good, dignity could be preserved (cf. Lindwall & Lohne, 2021).

The women with COPD expressed feeling stupid for having smoked, and described a perception of discrimination from healthcare personnel because of their smoking habit. The women also sensed that healthcare personnel were reluctant to share information regarding smoking cessation (I, III). This could be seen as an expression of suffering of care; violating a person’s dignity or worth by taking away their possibilities for strengthening their health (Eriksson, 2006; 2018). However, suffering can be alleviated, and Eriksson (1992; 2018) states that caring should ethically distance itself from all forms of condemnation, the exercise of power, and various forms of non-care. By safeguarding a person’s dignity and value as a human being, the purposes of caring ethics are fulfilled. Moreover, Laranjeira et al. (2022) state that people with advanced COPD tried to maintain motivation as

a reaction to poor healthcare encounters, in an effort to retain their dignity.

The findings show that women with COPD experienced healthcare encounters in which care differed, they were not taken seriously regarding their breathlessness and they felt ignored. This caused them to avoid seeking care though their health worsened which meant increased risk of their health and well-being (III). This could be seen as what Eriksson (2006; 2018) describes as violating a person's dignity and is one of the deepest forms of suffering. People living with incurable illnesses can experience being avoided or abandoned, as during healthcare encounters the women's illness can act as an uncomfortable reminder of failure to help for healthcare personnel (cf. Toombs, 1992).

In contrast, the women with COPD expressed that gentle, attentive, and systematic healthcare encounters made them feel involved, confirmed, and taken seriously (III). Eriksson (2018) states that a healthcare encounter must be based on attention, and a will to listen to and share the other person's story, suffering, and life circumstances. Through these, suffering can be alleviated (Eriksson, 1992; 2018). Moreover, alleviation of suffering can be achieved if healthcare personnel practice compassionate encounters (Arman, 2023) and if dignity is supported in care (Laranjeira, 2023). However, the skills of compassionate encounters could be taught in nursing education, and in clinical settings with different healthcare personnel. The process of the possession of this skill in healthcare encounters could be evaluated using empathy, sympathy, and altruism resulting in caring with compassion. Empathy is a natural and exercised ability to understand other people; sympathy is a desire to help the other person in suffering;

altruism means acting to increase the well-being of others and includes the responsibility to alleviate suffering (cf. Arman, 2023; Arman 2015).

Toombs (1992) values the human experience by avoiding categorizations as psychological or physical. This is essential because it highlights a key disparity between how practitioners can view diseases and how people experience them. Carel (2016) states that a good healthcare encounter is characterized by an equitable relationship between the ill person and healthcare personnel. According to Toombs (1992), understanding the illness experience reduces suffering, minimizes symptoms, and enables well-being. Skär et al. (2023) describe that people living with severe COPD have expressed that when healthcare personnel listened to them, they felt better, and found everyday life easier to handle.

# Methodological considerations

In this doctoral thesis, the concept of trustworthiness has been considered during the entire research process. This concept of trustworthiness, which includes credibility, dependability, confirmability, transferability, and authenticity is commonly used in qualitative research (Lincoln & Guba, 1985).

Credibility describes confidence in data, interpretation, and findings (Lincoln & Guba, 1985). The sample size in qualitative research should be large enough to achieve variations in experiences and include rich data, while remaining small enough to permit deep analysis (Graneheim et al., 2017). The sample size was considered sufficient to reach information power, as described by Malterud et al. (2016) for the four papers comprising the research for this thesis; see Table 2. I found the sample sizes sufficiently large to achieve variations in the studies presented in papers I–IV. In Paper III, one interview was only 15 minutes in duration, which could be seen as less information rich. However, the narrative gained was important and connected to the aim of the study, and confirmative of previous variations of the other 11 narratives. Therefore, I chose to include that specific interview.

In the studies presented in papers II and III, I attempted to be attentive and flexible while performing the interviews. The interviews were guided by opening questions that mirrored the aims of the studies. The qualitative content analysis was described step by step, making it possible for the reader to assess the credibility of the analysis. Further, quotations were selected from the interviews and presented in the findings (I, IV) to strengthen credibility.

In papers II and III, the analysis strove for possible meanings in a continuous process that contained three phases. The most probable

interpretation was presented in papers II and III, after mutual agreement between myself and my supervisors (cf. Ricoeur, 1976).

Dependability refers to the stability of data over time, and to the replicability of the research process (Lincoln & Guba, 1985). In the studies presented in papers I and IV, individual semi-structured interviews were performed based on an interview guide. A pilot interview was performed to test and validate the interview guide, and no changes were made; however, the pilot interview was not included because the participant did not meet the inclusion criteria. In the individual interviews, follow-up questions were used to stimulate answers (cf. Graneheim et al., 2017). I conducted all the interviews in the studies presented in papers I or IV; hence, all the interviews were performed in a similar manner throughout the studies. In the studies presented in papers II and III, narrative interviews were conducted. Giving the participants opportunities to add information, correct their answers, or ask questions, increased dependability. Using open-ended questions supported participants' capacity to provide detailed and rich narratives of their lived experiences. According to Lindseth and Norberg (2021), checking understanding during the interview process with probing questions, such as "What do you mean?" and "How did this make you feel?" strengthens dependability.

The outbreak of the COVID-19 pandemic in early 2020 made face-to-face interviews impossible. Telephone interviews were therefore used in the studies presented in papers I and IV. Two women in Paper III expressed a wish for face-to face interviews, which were obtained. Telephone interviews were acknowledged as effective for qualitative data collection, though face-to-face interviews are the gold standard (Uleanya et al., 2023).



Confirmability refers to the objectivity of the data (Lincoln & Guba, 1985). To achieve confirmability in the studies comprising this doctoral thesis, purposive sampling was used based on the inclusion criteria. In this thesis, the participants who were recruited were also willing to share their experiences. This allowed examination and analysis of various experiences of everyday life with COPD at stages III or IV (Lincoln & Guba, 1987). According to Polit and Beck (2021), a purposive sample contributes to a richer variation of the phenomena under study. The sample in the studies presented in papers I–IV varied regarding age, accommodation, marital status, rural or urban residence, education, and progression of illness. The sample was purposive, and the participants shared rich descriptions of the phenomena under study. In study IV, nine close relatives participated; while this could be regarded as a small size, the resulting interviews were rich.

Transferability refers to the extent to which qualitative findings can be transferred to another setting or group. The findings in the studies presented in papers I–IV cannot be generalized, although they may be transferred to other settings of people with long-term illnesses and similar contexts (Lincoln & Guba, 1985).

Authenticity includes fairness, the researcher’s background, clinical experience, education, and the way the researcher engages in data collection and analysis. During interviews, participants had the chance to further elucidate their responses and statements by asking questions. To address any potential impact on the collection, analysis, and interpretation of data, the approach involved ongoing conversations with both the research team and fellow doctoral students (cf. Lincoln & Guba, 1985).

Limitations include the use of mostly telephone interviews, related to the COVID-19 pandemic. While telephone interviews lack visual contact, they can still have impact and depth (cf. Uleanya et al., 2023; Novick, 2008). However, telephone interviews may help respondents feel more comfortable sharing sensitive information, and the interviews for this thesis were rich and deep. Another limitation is that I interviewed some of the women several times, which may have affected the findings in both positive and negative ways. The studies were conducted in a specific context i.e. geographical area, thus the findings are considered as well transferrable to similar contexts in other parts of the world.

In summary, the strength of this doctoral thesis is the rich interview data from the women with COPD at stages III or IV. In striving for authenticity, I have attempted to describe the participants' experiences in ways that enable the reader to see nuances and variations, and virtually hear the voices of the women with COPD and their close relatives (Polit & Beck, 2021). The rich data material was suitable for descriptions of the participants' lifeworld, the subjective world, and an alternative way of being-in-the world. This contributes to the strength of this thesis, as a deeper understanding of the women with COPD does show their possibilities for moments of feeling well, and for healthcare encounters that support and help them to enhance their health, and well-being, reduce suffering, and preserve their dignity.

# Conclusion

This doctoral thesis shows that women with COPD at stages III or IV experience both suffering and moments of feeling well during their everyday lives. Despite the unpredictability of their severe illness, these women have developed expertise in managing their everyday lives, which has enabled moments of feeling well. This has been facilitated by careful planning, a positive mindset, and support from close relatives. Furthermore, through knowledge about how to manage their ever-present breathlessness, they experienced feeling well. During healthcare encounters, the women wished for sufficient time to express their needs, continuity, and wished to be treated with respect. Positive, friendly approaches from healthcare personnel helped the women with COPD feel respected. The women expected clear, personalized information regarding their illness and possible treatments to better manage everyday life. In contrast, being seen as diagnose rather than as a person caused the women to feel ignored by healthcare personnel, and this had negative effects on their health and well-being. Furthermore, close relatives play an important role in supporting women with COPD during everyday life. Close relatives lacked knowledge and understanding of the women's ill health, and desired increased access to tailored information. Where this is possible, close relatives' capacity for support increases considerably.

The knowledge gained from this doctoral thesis about women with COPD at stages III and IV and their close relatives can be used to develop equal care in line with women's needs and resources.

## **Clinical implications and further research**

This doctoral thesis has explored, described, and generated knowledge about women's experiences of living with COPD at stages III or IV, and the experiences of their close relatives. However, the findings may be transferrable to additional settings of people with long-term illnesses and other similar contexts where people also often live at home. The implications for nursing in this doctoral thesis include that the findings can contribute useful information for stakeholders in preparing resources and organize care, at the hospital, in healthcare centers and in the community homecare settings. This could improve support, continuity in care, health, well-being, and reduce suffering for people with COPD. One such implication is the full adoption of person-centred care (cf. SOU, 2020:19).

The implications for caring in this doctoral thesis include that women described support from family, healthcare professionals, and digital communications channels as crucial. They reported they would like personalized information regarding their illness and possible treatments to enable them to improve management of everyday life. Close relatives also wished for increased knowledge and understanding of the illness COPD to enhance their important support. Based on the findings one suggestion could be the increased use of contact nurses. They could contribute with a more individualized, continuous care, coordinated multi-professional tailored support and information to help women with COPD and their close relatives better manage everyday life. This contrasts with other severe long-term illnesses, such as breast cancer, for which a designated contact nurse must be offered at the healthcare clinic at the time of diagnose. The aim of the contact nurse is to improve information and communication

between patients and care providers, to create accessibility, continuity, and security and to strengthen patients' opportunities to participate in their own care (cf. SOU, 2009:11).

The findings regarding meanings healthcare encounters show that positive and friendly approaches from healthcare personnel made the women with COPD feel respected. In contrast, experiences of COPD as a low priority in care and of being seen as a diagnosis made the women feel ignored by healthcare personnel, which had negative effects on their health and well-being. The findings indicate a need to raise awareness of this stigma and of approaches to create respectful encounters (cf. Lazare, 1987) among healthcare professionals who meet women with COPD at stages III or IV. Such healthcare encounters could be improved by listening to the women with COPD's expressions of their needs for support, and seeking to identify their resources.

Further research should aim to strengthen educational and competency needs for healthcare personnel in generic person-centred care (cf. Ekman et al., 2011) and within legislation. Evidence-based practice for people with pulmonary diseases merits promotion as a common goal among the nation, stakeholders, and academia. This doctoral thesis elevates the voices of women with COPD and their close relatives, but further need remains for research delineating the perspectives of healthcare personnel.

Women with COPD expressed perceiving themselves as experts of their own illness, but at the same time requested personalized information regarding their illness and possible treatments. This raises questions regarding health literacy, which includes the abilities to discuss, evaluate, and interpret information, and to ask questions and find information. Lack of health literacy could constitute obstacles: for

example, participation in rehabilitation, patient education, and medication compliance.

The findings from this doctoral thesis show that women with COPD have developed expertise in managing their everyday life to enable moments of feeling well. This raises questions of measuring and studying health broadly using the St George's Respiratory Questionary (SGQR) specific for assessing health-related quality of life in respiratory patients (Jones et al., 1991), and sense of coherence approach (cf. Antonovsky, 1987) for both people with COPD and their close relatives to further promote health and well-being.

## Summary in Swedish

Denna doktorsavhandling i omvårdnad har studerat upplevelser i dagligt liv hos kvinnor med svår kronisk obstruktiv lungsjukdom (KOL), samt upplevelser hos deras närståendes upplevelser. Kronisk obstruktiv lungsjukdom är en ofta förekommande komplex sjukdom som påverkar alla aspekter av vardagen hos de drabbade personerna. Doktorsavhandlingens resultat visar att kvinnor med KOL levde ett dagligt liv som var mycket starkt påverkat sjukdomen. Kvinnorna var tvungna att planera sitt dagliga liv i detalj och hade förvärvat expertkunskap om sin kropp, sin andning och hanterar oförutsägbar ständigt närvarande andnöd i alla vardagens aspekter. Stöd från familj, vårdpersonal och digitala medier var avgörande (I). Kvinnor med KOL upplevde att de mådde bra när de fick stöd. Att må bra innebar att kvinnorna upplevde en omedvetenhet om sin andfåddhet vilket möjliggjorde känslor av självständighet, värdighet och samhörighet. Att hitta glädje i vardagen bidrog till att de mådde bättre (II). I vårdmöte värderade kvinnor med KOL det positivt när de fick tillräckligt med tid att uttrycka sina behov och att bli bemött som en person och inte som en diagnos. Att känna sig försummad ledde till att de inte kände sig bekräftad. Om kvinnorna de inte blev lyssnad på, eller togs på allvar, fanns en risk för stigmatisering och påverkan på kvinnornas hälsa och välbefinnande (III). Närstående upplevde stress och svårigheter att fullt ut förstå svårigheterna av kvinnornas sjukdomstillstånd och efterlyste skraddarsydd information (IV).

Doktorsavhandlingens resultat har diskuterats i ljuset av Katie Erikssons teori om *The suffering human being*, Havi Carels forskning om *Phenomenology of illness* och Kay Toombs forskning *The meaning of illness* samt tidigare forskning.

Resultatet visar att kvinnor med KOL stadium III eller IV levde med en ständigt närvarande andfåddhet som tolkades som ett uttryck för sjukdomslidande. Detta sjukdomslidande försökte kvinnorna undvika genom planering och att ha god självkänedom om sin kropp och andning. För att i stället minska lidandet och stödja hälsa och välbefinnande hos kvinnor med KOL stadium III eller IV och deras närstående, skulle digitala medier möjliggöra säker och kontinuerlig hjälp i kontakt med hälso- och sjukvårdspersonal. Kvinnor med KOL stadium III eller IV upplevde sig fångade i sin andfåddhet och behövde ofta hjälp och stöd (I, II). På grund av sin svåra sjukdom hade de drabbats av många förluster (II).

Livslidande innebär att en människas dagliga liv förändras i termer utifrån vad personen är van vid. När en människa drabbas av ett hot som sjukdom kan det ses som ett uttryck för livslidande. Kvinnor med KOL stadium III eller IV upplevde att sjukdomen fick dem att tänka på och förbereda sig för sin död vilket gav dem upphov till känslor av försoning. Kvinnorna med KOL stadium III eller IV ville samtala med sina närstående och sjukvårdspersonal för att förbereda inför sin död (II). Kvinnor med KOL hindrades av sjukdomen att göra vad de önskade på grund av förlust av förmågor vilket genererade känslor av frustration, eftersom sjukdomen gradvis blev värre. Detta påverkade kvinnor med KOL och deras känsla av oberoende (I, II). Stöd från närstående innebar att närstående agerade som förlängning av kvinnornas kroppar och som en hjälp till kvinnorna att ta hand om sig själva för att må bra (II, IV). Kvinnor med KOL stadium III eller IV upplevde att de blev nedprioriterade i mötet med hälso- och sjukvårdspersonalen och ibland till och med försummade när de sökte hjälp för sin svåra andfåddhet. I dessa situationer upplevde kvinnor att de blev sedda som en diagnos och inte som en person (III). Detta kan ses som ett uttryck för vårdlidande som är ett onödigt lidande där den vårdande dimensionen saknas. I den helande relationen mellan



den person som söker hjälp och sjukvårdspersonalen, bör uppmärksamheten riktas mot upplevelsen hos den som är sjuk snarare än på sjukdomsprocessen. Att bli försummad (dvs. att inte bli sedd som en person) är ett uttryck för att den andra personen (patienten) upplevs som ett objekt.

Sammanfattningsvis visar denna doktorsavhandling att kvinnor med KOL stadium III eller IV upplever både lidande och stunder av att må bra i sin vardag. Trots oförutsägbarheten i sin svåra sjukdom har kvinnor utvecklat expertis i att hantera sin vardag och möjliggöra stunder av att må bra. Detta underlättas av en noggrann planering, ett positivt tänkesätt och stöd från närstående. I mötet med hälso- och sjukvårdspersonalen saknade ibland kvinnorna tillräckligt med tid för att uttrycka sina behov och bli bemötta med respekt. Ett positivt och vänligt bemötande från vårdpersonal fick kvinnor med KOL att känna sig respekterade. De förväntade sig tydlig, individuell information om sjukdomen och möjliga behandlingar, för att bättre hantera vardagen. Att ses som en diagnos gjorde att kvinnorna kände sig försummade av vårdpersonal och det hade en negativ effekt på deras hälsa och välbefinnande. Närstående har en viktig roll att stödja kvinnor i vardagen, men de behövde skraddarsydd information om KOL. Kunskapen från denna doktorsavhandling om kvinnor med KOL stadium III och IV och deras närstående är viktig och betydelsefull för sjuksköterskor för att kunna möta kvinnornas behov och resurser för en individuell utformad vård och omvårdnad.

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