

Living with chronic obstructive pulmonary disease stage III or IV from the perspective of the affected women and their close relatives. A qualitative study

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To my family

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Abstract

Living with chronic obstructive pulmonary disease stage III or IV has a major impact on a person's everyday life. The aim of this licentiate thesis was to describe the experiences of women living with chronic obstructive pulmonary disease stage III or IV, as well as the experiences as a close relative to women with chronic obstructive pulmonary disease stage III or IV. In both studies, data were collected through individual, semi-structured interviews. The interview texts were then subjected to qualitative content analysis. A purposive sample of 15 women with either stage III or IV chronic obstructive pulmonary disease stage and a total of 9 close relatives participated in the studies. The findings showed that breathlessness restricted women with chronic obstructive pulmonary disease, to live with a breathing and body which they had to wait for. Stabilizing an ever-present breathlessness by restoring strength helped them manage everyday life and adapt to their limited abilities and energy. This restoration required detailed planning and a good knowledge of their breathing and bodies. Women were afraid of contracting life-threatening infections that would cause suffering. Fear led to isolation, and digital media were described as an important means of communication (I). Close relatives were of major importance to women with chronic obstructive pulmonary disease in their everyday life in terms of being flexible to accommodate the women's needs. They were flexible, available, and on stand-by. The COVID-19 pandemic was experienced by close relatives as a reinforced threat to women with chronic obstructive pulmonary disease. Close relatives raised awareness of their vulnerability to potentially life-threatening infections, leading them to carefully avoid exposure and thus rely more on digital media. A more sedentary life was one effect of living in a gradually, yet controlled everyday life for close relatives. Women with chronic obstructive pulmonary disease stage III or IV and their close relatives expressed that they lacked continuity, participation, and support from healthcare professionals (I, II). In conclusion, the findings of this licentiate thesis show that women with chronic obstructive pulmonary disease stage III or IV and their close relatives experience both health and suffering in their everyday lives. By gaining understanding and insights into the lives of women with chronic obstructive pulmonary disease, as well as the needs and everyday challenges of their close relatives, better health outcomes can be supported.

Keywords: Health, Interviews, Nursing, Pulmonary Disease Chronic Obstructive, Qualitative research, Relatives, Suffering, Support, Women

Summary in Swedish

Denna licentiatavhandling i omvårdnad fokuserar på dagligt liv för kvinnor med kronisk obstruktiv lungsjukdom (KOL) stadium III eller IV och deras närståendes upplevelser. Att leva med en långvarig sjukdom som KOL påverkar det dagliga livet i stor utsträckning för både den sjuke personen och deras närstående. Kronisk obstruktiv lungsjukdom är en vanlig långvarig sjukdom som leder till en successiv nedsättning av lungfunktionen och därmed andningsförmågan. Fler kvinnor dör i KOL i Sverige idag jämfört med tidigare på grund av framförallt förändrade rökvanor. Tidigare forskning visar att närstående ger praktiskt och emotionellt stöd i dagligt liv till personer med KOL och att detta kan vara mycket utmanande över tid. Dessutom visar tidigare forskning att hälsan hos kvinnor med KOL i alla stadier av sjukdomen samt deras närstående påverkas på flera olika sätt.

Syftet med licentiatavhandlingen var att beskriva kvinnors och deras närståendes upplevelser av att leva med KOL stadium III eller IV. Licentiatavhandlingen har en kvalitativ ansats och genomfördes genom att 15 kvinnor med KOL i stadium III eller IV (I) och nio närstående till kvinnor med KOL i stadium III eller IV (II) intervjuades individuellt. Intervjuerna genomfördes per telefon på grund av pandemin. Deltagarna uppmanades att berätta om hur de upplevde att leva med KOL i sitt dagliga liv. Intervjuerna spelades in och skrevs ut ordagrant för att därefter analyseras med kvalitativ innehållsanalys. Analysen i delstudie I resulterade i ett tema och tre kategorier. Analysen i delstudie II resulterade i ett tema och fem kategorier. Resultatet visar att kvinnor med KOL stadium III eller IV beskrev att deras dagliga liv bestod av att stabilisera en ständigt varierande andfåddhet. Detta innebar att kvinnorna behövde hushålla med sina krafter och anpassa sig efter sin kropp som de måste vänta in. Detta krävde detaljerad planering och att vara expert på sin egen andning och kropp. Kvinnorna med KOL stadium III eller IV var rädda för att få livshotande infektioner som skulle kunna orsaka lidande i form av kvävningsskänslor, särskilt COVID-19. Rädslan ledde till självisolering och digitala medier beskrevs

som ett viktigt kommunikationsmedel. Kvinnorna med KOL stadium III eller IV saknade att möta samma person för att inte behöva återberätta sin sjukdomshistoria vid kontakter med hälso och sjukvården.

Närstående till kvinnor med KOL stadium III eller IV beskrev att de var flexibla och på stand-by. De var uppmärksamma på vilka behov kvinnorna hade och att hantera dessa utifrån deras rådande hälsa. Närstående beskrev att deras gemensamma dagliga liv fokuserade på att leva med variationerna av KOL och att se möjligheter i detta. De beskrev kvinnornas sårbarhet för livshotande infektioner, vilket gjorde att de var mycket aktsamma med att undvika att överföra eventuell smitta. COVID-19-pandemin ökade kraftigt de närståendes oro. Närstående menade att användningen av digitala medier var ett sätt för att minska kvinnornas isoleringen, och därmed minskade även deras egen oro. Digitala medier var även en möjlighet att umgås och att ge viss praktisk hjälp. Denna licentiatavhandling visade att kvinnor med KOL stadium III eller IV levde med en ständigt närvarande andfåddhet som tolkades som ett uttryck för sjukdomslidande. Kvinnorna levde med en rädsla för att drabbas av en potentiellt livshotande infektion som skulle kunna leda till ökat lidande i form av kvävningsskänslor. Detta lidande försökte kvinnorna undvika genom planering och att ha god självkänedom om sin kropp och andning. Samtidigt betonades att kvinnorna och deras närstående saknade kontinuerligt stöd och hjälp från hälso och sjukvårdspersonal. 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. E-hälsa skulle kunna vara ett område för vidareutveckling för att tillhandahålla vård.

List of papers

This licentiate thesis is based on the following studies, referred to in the text by their Roman numerals:

- 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*. Advanced online publication. <https://doi.org/10.1111/scs.12998>

- II. Ekdahl, A., Söderberg, S., & Rising-Holmström, M. (submitted). Experiences from close relatives of a women with stage III or IV chronic obstructive pulmonary disease: a qualitative study.

Reprints were made with permission from the publisher of Paper I.

Preface

My interest in people living with long-term illnesses developed when I was working as a clinical research nurse. I worked for many years in clinical trials involving people with long-term illnesses, mostly cancer. I learned a lot about the research process and systematic procedures, and my curiosity grew. Clinical trials for people with cancer—in particular, women with breast cancer—often include individuals with advanced disease, where a cure is not possible. Meeting with those women and their relatives over time has given me insight and a fascination regarding what registered nurses (RNs) can do to promote health for individuals living with advanced long-term illness until the end of life. At the time, I was privileged to work with an organization that had an academic approach, and physicians and RNs worked in high-functioning outpatient teams for persons with cancer. I had enough time to spend on each patient that each patient felt content with the care delivered, which led to the opportunity to create relationships between me and the patients, building trust, hope and the space to listen to their desires and fears. However, my curiosity and ambitions eventually grew to professional frustration, which led to my decision to apply to university. My pre-understanding, experiences, and knowledge from my early work experience have inspired and motivated this licentiate thesis.

Introduction

This licentiate thesis is written in the field of nursing science and focuses on women with chronic obstructive pulmonary disease (COPD) stage III or IV and their close relatives. The metaparadigm of nursing science consists of the following four concepts: humans, environment, relations, and health (Fawcett, 2005). According to Eriksson (2018), health is the main purpose of nursing; health can be described as a natural phenomenon that is a part of all people's lives. In this licentiate thesis, the focus is on understanding health and illness from a persons perspective (i.e., women and their close relatives) in their everyday lives (Dahlberg, 2010).

Background

Health and ill health

The concept of health, though discussed from different perspectives, generally deals with the view of human beings and their current context in society. The most familiar concept of health is often described in polarized terms, consisting of the biomedical and the humanistic contexts. In the biomedical context, health is described as the absence of disease (Nordenfelt, 2007). In the humanistic context, health is described as when a person has maintained abilities and is seen as a whole. Over time, as the concept of health has increasingly shifted more towards experiences, aspects of quality of life and well-being have been included in the definition of health (Nordenfelt, 1987). According to Eriksson (2014), health is described as either a condition or as a process, with process emphasizing “having health” and “to be healthy”. Further, Eriksson (2018) explains that the concept of illness refers to the subjective experience of ill health. Understanding health, finding a way toward health, and supporting the inner health of a person involves developing and promoting the person’s self-support (Eriksson, 2018). When a person is living with an illness such as COPD stage III or IV, their experience of health can change due to losses of

bodily functions, loss of abilities, and gradual deterioration (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2021). According to Stridsman et al. (2015), people with COPD stage II- IV described good days when they could breathe and there was a balance between breathing and viability and they experienced increased well-being.

Women's health

Women are more likely than men to experience serious illness, including COPD, and to have co- or multimorbidity (European Commission, 2014). Globally, women with long-term illnesses, such as cardiovascular disease, breast cancer, diabetes, or COPD, are at risk for death and ill health. Further, major depressive disorders and musculoskeletal conditions are the main cause of morbidity and ill health among women (Osika Friberg et al., 2016; Wijma et al., 2010). The globally higher prevalence of ill health among women and their limited access to and use of care is well known (Doyal, 1995; Osika Friberg et al., 2016). Various behavioral, socioeconomic, sociocultural, environmental, and clinical factors have likely contributed to the rising prevalence over time of COPD in women (Aryal et al., 2014; Axelsson-Fisk, 2021). Previous research shows that one contributing behavioral factor is that women are overrepresented in symptom reporting and discussing health (Malterud, 1987). These behaviors are furthermore presumed to influence coping strategies and sensitivity to illness (Hammarström, 2005). Smoking is the most common cause of COPD (GOLD, 2021), and breathlessness is a clinical factor and a hallmark symptom in more severe COPD (Åberg et al., 2019). Breathlessness is also more frequently reported in women, which has an impact on health status and quality of life (Miravittles & Ribera, 2017). Women today have adopted the lifestyle of men when it comes to smoking (Vanfleteren et al., 2020). Smoking is just one example of a socioeconomic factor that can illustrate the link between education and health (Huisman et al., 2005). One sociocultural factor affecting women's health is that society may consider COPD to be self-inflicted

(O'Neill, 2002). Consequently, this could lead to vulnerability among women because of experiences of self-blame, blame from healthcare professionals, and reluctance to seek care. Another possible consideration in the development of COPD is that 80% of nonsmoking COPD subjects are women (Aryal et al., 2014). One environmental factor could be that women tend to be in charge of cooking at home and thereby breathe in pollutants (GOLD, 2021). People with COPD constitute a vulnerable group because of their severe symptoms, multiple co-morbidities, and lower socioeconomic status than the general population (Grigsby, 2016; Yildirim et al., 2013).

Living with long-term illness

People living with long-term illnesses have described their everyday life as being characterized by limitations and restrictions. These restrictions consist of what the person can no longer do (Ahlström, 2007; Kralik, 2002; Kralik et al., 2004; Nätterlund, 2001; Scherman et al., 2002; Öhman et al., 2003). According to Corbin (2003), it appears that there must be an interference with the activities of everyday life or a certain degree of severity before persons with long-term illness perceive themselves as ill. To suffer from long-term illness means to suffer from changes, changes that also affect close relatives, a phenomenon which has been noted in various progressive illnesses as well (Corbin, 2003; Eriksson et al., 2019; Jumisko et al., 2007; Söderberg et al., 2003; Öhman et al., 2003). It is important to have a balance in everyday life, and this means that people are striving for independence (Nilsson et al., 2016). Women with long-term illness have described the illness as an intrusion, meaning that they feel their lives will never be the same. In some studies, this disturbance has been shown to affect self-perception (Kralik et al., 2001). According to Kralik et al. (2004), women diagnosed with a long-term illness described feeling alone, vulnerable and lost and that they lacked adequate information as they tried to understand the meaning and the consequences that the diagnosis holds for their present and future. It can be difficult to

maintain social contacts and relationships because long-term illness can lead to a loss of energy, and the ill person may feel a sense of being a burden on their close relatives (Charmaz, 1983). Living with a long-term illness can be viewed as a disruption of the body, but it can also be seen as a threat to the very self (Toombs, 1992), including past, present and future conceptions (Corbin, 1987). According to Toombs (1995), the experience of illness is subjective, has to do with losing bodily functions, and is based on how the experience of illness is understood in daily life. People with illness can achieve meaning and dignity by having someone to share their losses and difficult experiences so that they can carry on living (Toombs, 1995). Further, the experience of illness includes close relatives and enduring enables them to “get through” and to “be there” for their family members (Morse & Jonsson, 1991; Morse, 2018).

Chronic obstructive pulmonary disease: a long-term illness

By the year 2030, COPD is expected to be the third most common cause of death globally (GOLD, 2021). The Global Initiative for Obstructive Lung Disease (2021) 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. The estimated prevalence of COPD for all stages in Sweden is 400,000-700,000 individuals, and the prevalence for women are approximately 6% (Backman et al., 2016). The total prevalence of COPD is now equal between men and women (Lisspers et al., 2019). The prevalence of people living with COPD stage II-III is 3-5% (Backman et al., 2020). COPD receive less attention and funding than other long- term illnesses that have equal impact (Williams et al., 2020). The main risk factor for COPD is tobacco smoking. In recent year, women have changed their smoking habit patterns (GOLD, 2021) which explains why an imposing significant healthcare disease burden among women is expected in the future (Lisspers et al., 2019). Like many serious illnesses, COPD is a mild disease initially, but it is progressive and currently incurable (GOLD, 2021). Among people

with COPD, of all stages, life expectancy is shorter, than among the average Swedish population (Ställberg et al., 2014). The course of COPD stage III and IV is characterized by persistent respiratory symptoms and airflow limitations that gradually worsen. The most common symptoms of COPD stage III or IV are cough and sputum production, fatigue and severe dyspnea, which causes feelings of anxiety and suffocation (Andrade et al., 2003; GOLD, 2021; Lisspers et al, 2019; Seamark, 2004; Stridsman et al., 2014; Ställberg et al., 2014). Oxygen treatment at home is very common in patients with COPD stage IV. In COPD stage III or IV, other medical complications arise such as respiratory failure, heart failure, and loss of weight (GOLD, 2021). As the illness progresses, the need for support increases, with individuals with COPD stage III or IV eventually becoming dependent on help and support (GOLD, 2021).

Living with chronic obstructive pulmonary disease

People with COPD live their everyday life influenced of breathlessness (Fraser et al., 2006; Johansson et al., 2019; Miravittles & Ribera, 2017), this can cause feelings of anxiety, helplessness, and suffocation (Bailey, 2004; Seamark et al., 2004). For those living with COPD stage III or IV, their symptom burden has a major impact on their everyday life and can eventually lead to the need for palliative care. The symptom burden can lead to feelings of fear of suffocation and awareness of death (Ek et al., 2015; Johansson et al., 2019; Strang et al., 2014; Ek & Ternstedt, 2008). Generally, healthcare support aims to reduce symptoms for people with COPD and avoid periods of deterioration. More frequent follow-ups are required during periods of worsened symptoms, and less frequent follow-ups are needed during better periods. A COPD nurse may coordinate follow-ups individually (GOLD, 2021). According to Ali et al. (2021), people with severe COPD saw an increase in their confidence in managing their illness when they were included in an intervention with nurse-led, telephone-based,

person-centered care where the telephone support was added to usual care.

Women with COPD seems to have a more severe form of exacerbations, suffers more often from shortness of breath and deterioration than men (de Torres et al., 2005; GOLD, 2021; Kokturk et al., 2016). Notably, women with COPD have longer hospital stays and are more frequently in-patient as they suffer from exacerbation episodes due to infections (de Torres et al., 2007). Women with COPD struggle with burdensome symptoms, loss of jobs, reduced social activities, and strained family relationships. By living with COPD women often develop coping strategies to handle and prevent symptoms from their illness, using an action plan to feel safe. To use those strategies, women with COPD have reported that they desire greater education, supervision, and healthcare professionals who knew their story. Social relationships also helped them better live with the illness (O'Neill, 2002; Steindal et al., 2017). They restrict their activities to avoid deterioration due to weather extremes, tobacco smoke or isolate themselves.

According to Jonsdottir and Jonsdottir (2007), women with COPD experienced being caught in a kind of spider web related to smoking relapses. A greater focus on the woman as an individual beyond the physical symptoms has been described as important when supporting smoking cessation (Nykqvist et al., 2014). Objectively, women's perceived quality of life is low according to multiple instruments that have examined various aspects of quality of life and disease-specific factors such as dyspnea, mucus-formation, and cough (Gore et al., 2000; Habraken et al., 2008; Watson, et al., 2006).

Close relatives to people with chronic obstructive pulmonary disease

The role of close relatives is significant in supporting people with COPD in their everyday life (Nakken et al., 2015), and people with COPD prefer to be cared for in their own home (Miravitlles et al., 2015). Most research about the experience of close relatives of people with COPD has previously addressed all stages of the illness (Andersen et al., 2018; Andrade et al., 2003; Badr et al., 2017; Figueiredo et al., 2014; Jácome et al., 2014; Kokturk et al., 2016; Lindqvist et al., 2013a; Lindqvist et al., 2013b; Lisspers et al., 2019; Marques et al., 2015; Miravitlles et al., 2015; Siltanen et al., 2019; Stridsman et al., 2014; Ställberg et al., 2014; Yohannes et al., 2018).

Close relatives will probably be more involved in supporting woman with advanced COPD in their everyday life. The burden of close relatives is therefore dynamic and gradually changing. Women living with advanced COPD may become more care-dependent over time and according to Lindqvist et al., (2013a). Everyday lives of close relatives gradually become affected, and the relationships change (Lindqvist et al., 2013a; Lindqvist et al., 2013b; Kanervisto et al., 2007; Sundh & Ekström, 2016). Close relatives of severely ill family members are the main providers of support and help for people with COPD (Ek et al., 2015).

According to Bagnasco et al., (2021) close relatives of persons with COPD can feel abandoned, isolated, and need respite from their role. Sigurgeirsdottir, et al., (2020), stated that challenges for close relatives were expressed as fear of exacerbations, anxiety due to the unpredictability of the COPD illness, and their reluctance to be co-dependent. Further, a loss of intimacy can lead to psychological distress, including feelings of powerlessness for close relatives (Andersen et al., 2018; Badr et al., 2017; Marques et al., 2015; Siltanen et al., 2019; Sundh & Ekström, 2016; Yohannes et al., 2018), which can affect close relatives' quality of life (Jácome et al., 2014). Close relatives

of people with COPD often experience an overwhelming feeling of duty to care for and help maintain the integrity and self-esteem of the ill person (Lindqvist et al., 2013a; Lindqvist et al., 2013b). According to Nakken, et al. (2015), close relatives have described their experiences as an opportunity for personal growth. As the COPD illness is perceived as self-inflicted can mean that close relatives' relationships with the person with COPD might be negatively affected (Fusi-Schmidhauser, et al., 2020). Moreover, the strain of bearing witness to their partner's illness deterioration could create a sense of shared suffering (Hynes et al., 2012). The role of close relatives is often indistinct, and their expertise is not always acknowledged by healthcare professionals (Gardiner et al., 2010). Furthermore, healthcare professionals often miss seeing the close relatives needs (Farquhar, 2018). The health of close relatives' can also be affected, including they can lose their previous lifestyle and it can affect their occupation as well as their personal freedom (Miravittles et al., 2015; Stridsman et al., 2014; Sundh & Ekström, 2016). When interviewed, close relatives expressed a desire to be involved in healthcare appointments in the whole-care process (Cruz et al., 2017), and to receive sufficient information and support from healthcare professionals (Spence et al., 2008).

Suffering and enduring illness

Long-term illness such as COPD stage III or IV can be a threat to life itself and confronts people with experiences of suffering. Eriksson (2018) clarifies that the opposite of health is not illness but suffering, if it is bearable. Suffering is a part of health, and health is compatible with enduring suffering, i.e., a person who suffers can experience health at the same time (Eriksson, 2018). Suffering violates human dignity and implies loss and death, but also the possibility of new life and reconciliation (Eriksson, 2018). Eriksson (2018) categorizes suffering into one of three forms: suffering of illness, suffering of care, and suffering of life. Suffering of illness originates from a disease or its

treatment and may include having a disabled body. Suffering of care refers to when a person's dignity is violated in care, such as in situations where a person is not believed or taken seriously. Neglect of care is a form of uncaring; this fits within Eriksson's category of suffering of care. Suffering related to life is experienced in relation to one's own unique life, for example whether to live or not, the meaning of life and living the various phases of life changes during developmental stages and life events (Eriksson, 2018). Morse and Carter (1996) identify three types of enduring: enduring to survive, enduring to live, and enduring to die, such as in serious illness or in the trajectory from illness to dying. According to Morse and Carter (1996), people hover between suffering and enduring. The suffering continues until they can accept the changed reality; then, people can gain new insights and appreciation for life as a reformulated self.

Rationale

The burden of COPD in women is considerable and growing in Sweden. Living with COPD stage III or IV has a major impact on women's everyday lives, and close relatives are of significant importance in terms of support. To the best of my knowledge after reviewing the literature, there is a lack of research describing the experiences of women with COPD stage III or IV and the experiences as a close relative to women with COPD stage III or IV. Previous research has first and foremost addressed the experience of women with all stages of COPD and their close relatives. The knowledge from this licentiate thesis can add new and better opportunities to meet the needs of both women and their close relatives in order to support their health and well-being in everyday life. Furthermore, generated knowledge can help healthcare professionals to provide additional layers of support to increase health and well-being.

Aim

The overall aim for this licentiate thesis was to describe the experiences of women living with COPD stage III or IV and the experiences of their close relatives. Specific aims of the papers:

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 describe experiences as a close relative to women with COPD stage III or IV.

Methods

The naturalistic perspective

This licentiate thesis falls within a naturalistic perspective, since naturalistic inquiry is based on the belief that context is necessary for understanding human behavior (Lincoln & Guba, 1985). This licentiate thesis aims to describe the experiences of women living with COPD stage III or IV, and describe experiences as a close relative to women with COPD stage III or IV. The naturalistic perspective looks at a research question in its natural context, without intervention, as a means to create and discover knowledge. The researcher is the instrument of inquiry. Through genuine and respectful relationships between the researcher and the participants, developed during interviews, the researcher is able to collect data with increased depth and richness (Lincoln & Guba, 1985). The researcher does not attempt to influence, control, or manipulate what is occurring naturally (Patton, 2015). This approach is also called a natural environment of the participants' world (Lincoln & Guba, 1985); for example, the researcher meets the person in their home to conduct an interview about how they experience their daily life. In this licentiate thesis, open-ended questions were posed in a natural environment to women with COPD stage III or IV and to their close relatives in order to obtain descriptions of their experiences.

Pre-understanding

In all research and especially in qualitative research, where the researcher is the instrument, it is crucial to clarify pre-understanding. This is because of the critical importance of being open throughout the process of analysis, continuously reflecting upon my background, experience, education, and my way of engaging in data collection and striving for trustworthiness (Patton, 2015). Reflexivity involves acknowledging our pre-understanding; otherwise, we run the risk of our results only reflecting ideas that already exist in our own

understanding (cf. Dahlberg et al., 2008). I have tried to be aware of my pre-understanding, to set aside beliefs, and to be open-minded about the research questions. My pre-understanding comes from my role as an RN with extensive clinical experience working with patients with long-term illnesses, mostly in outpatient care. Further, I have had continuous and critical discussions with my supervisors, who are both senior researchers and RNs themselves. Through this cooperation, our different and similar angles have contributed to my awareness of my pre-understanding.

Design

This licentiate thesis used a qualitative descriptive design, as the aim was to describe the experiences of women living with COPD stage III or IV as well as to describe experiences as a close relative to women with COPD stage III or IV. Qualitative design is suitable when addressing issues regarding experiences and when the purpose of the research questions is to understand without predetermined factors (Patton, 2015). An overview of the study aim, design, method, participants and data collection of the two papers is presented in Table 1.

Table 1. *Overview of study aim, design, method, participants and data collection*

Paper	Aim	Design	Method	Participants	Datacollection
I	The aim of this study was to describe women's experiences of living with COPD stage III or IV.	Qualitative descriptive	Qualitative content analysis	Fifteen women with chronic obstructive pulmonary disease stage III or IV	Individual semi-structured interviews
II	The aim of this study was to describe experiences as a close relative to women with COPD stage III or IV	Qualitative descriptive	Qualitative content analysis	Nine close relatives of a woman with chronic obstructive pulmonary disease stage III or IV	Individual semi-structured interviews

Context

The two studies in this licentiate thesis were conducted in a region in the middle of Sweden with a population of 245,000 inhabitants. The region is considered sparsely populated, with a mix of urban and rural areas, where almost a third of the population lives in rural areas. (Statistics Sweden, 2021).

Participants

Paper I

A purposive sample of 15 women with COPD stage III or IV participated in this study. According to Patton (2015), a purposive sampling selects information-rich cases whose study will illuminate the research questions in depth. The sample was based on a model of sample size in the qualitative selection and information power (Malterud, 2016). The participants in this study shared their experiences that were specific and related to this study's aim and representative, which enhanced information power. This model describes ways to reach the number of participants needed concerning the information generated by the sample (Malterud, 2016).

The inclusion criteria were participants age >18 years, with a diagnosis of COPD stage III or IV, and the ability to speak and understand Swedish.

Paper II

A purposive sample of nine close relatives participated in this study. The women with COPD (I), decided whom to consider as their close relatives. Out of fifteen possible close relatives, nine chose to be contacted for an interview.

An overview of the participants (I, II) is presented in Table 2.

Table 2. *Overview of the participants in (I, II)*

Characteristics	Paper I	Paper II
Age, md (m, min-max)	75 y (72, 50-84)	57 y (45-85)
Participants, n	Women (15)	Close relatives (9) Husbands (3) Cohabitant, male (1) Daughters (3) Friends, female (2)
Education level, n	Secondary school (4) High school (7) Higher education (4)	(6) (3)
Retired, n	(14)	(4)
Part time working, n	(1)	(5)
Living alone in flat, n	(9)	
Living with husband or spouse, n	(5)	(4)
Living in Nursing home, n	(1)	
Home care, n	(4)	
Ex-smoker, n	(11)	
Never smokers, n	(2)	
Years living with COPD, md (m, min-max)	10 (12, 2-30)	
Oxygen at home, n	(7)	
Experience of patient education, n	(3)	
Specialized contact nurse, n	(3)	

Procedure

Paper I

The pulmonary medicine department at a hospital in the region assisted with recruitment of participants. A secretary distributed invitation letters based on the inclusion criteria to women with COPD stage III or IV. They received information about the study, an informed consent form and a reply form. Out of 50 that were invited, fifteen women gave permission to participate and sent their reply forms to the university. The women were then contacted by phone and an appointment for an interview was made.

Paper II

Women with COPD stage III or IV whom were participating in (I) administrated invitation letters to their close relatives about the study for (II). Out of fifteen possible close relatives, nine chose to be contacted for an interview. Once the consent forms were returned interviews were arranged at a time convenient to the close relatives who had accepted the invitation to participate.

Data collection

Data were collected using qualitative individual semi-structured interviews and were conducted with women with COPD stage III or IV (I) and their close relatives (II). Qualitative research based on data from interviews requires understanding and cooperation between the researcher and the participants. In the interview situation, the interviewer and the participants can maintain a conversation moving back and forth both in the present time and to the past to clarify the understanding (Brinkman & Kvale, 2015). The interview guide was designed to elicit descriptions of experiences in their everyday life guided by the aim. Semi-structured interview questions are designed to be brief and simple to allow participants to provide as much dialogue as possible (Brinkman & Kvale, 2015). An interview guide was developed as a tool for collecting data and was tested in a pilot

interview, which has been described to be useful (Kallio et al., 2016). The interviews were conducted March–May 2020 by telephone due to the COVID-19 pandemic. According to Musselwhite et al., (2007) telephone interviewing is an effective method of data collection when the procedure is well prepared. When the participants in (I, II) were contacted for the purpose of arranging the interviews, they were given the opportunity to choose the time they preferred. Women with COPD stage III or IV were also informed that they could choose to split up the interview into two sessions if they were lacking strength or got too breathless while speaking. They were also offered pauses or breaks, although none accepted. At the time of the interview, all the participants were verified, to ensure the interviewer was speaking with the correct person. In addition, they were asked to be seated in a private room separated from their relative, if they were in the same home. After the interviews the participants were informed that they could contact the interviewer if they had any additional questions.

Paper I

Women with COPD stage III or IV were asked to describe their experiences living with the illness. The interview guide addressed to women with COPD, contained questions such as “Tell me about your everyday life with COPD stage III or IV”, “Tell me if and how your relationships with family, friends, others are affected”, “Tell me about your experience when you are feeling less well”, “Who do you turn to if you need help with something about your illness?” and “Tell me about your contacts with healthcare professionals.” Clarifying and encouraging questions were asked, including “Tell me more about that” and “Can you give an example?” The interviews lasted between 32 and 118 minutes (median=60 min).

Paper II

The close relatives were asked to describe their experiences as a close relative to a woman with COPD stage III or IV. The interview guide had questions in three main topics, everyday life, relationship's to family, friends and others (healthcare), clarifying and encouraging questions were asked, "Can you tell me more about that?" and "Can you give an example?" The interviews with close relatives to women with COPD stage III or IV lasted between 39 and 76 minutes (median= 62 min).

The interviews in study I and II were recorded and transcribed verbatim.

Data analysis

Qualitative content analysis is generally used when a study design has the aim to describe a phenomenon. The method for analyzing qualitative data focuses on content, and variation as a means of developing an extended knowledge of the human health and illness (Granheim & Lundman, 2004). Qualitative content analysis in nursing research has been applied in both quantitative and qualitative data and to a variety of depths of interpretation. The inductive approach involves a text-driven search for patterns. The deductive approach is defined as concept-driven and tests the implications of existing theories (Granheim & Lundman, 2004).

This licentiate thesis has an inductive approach and the interview texts in both studies were subjected to qualitative content analysis following the guidance of Graneheim and Lundman (2004). Manifest content deals with what the text says and describes the visible and obvious. Latent content deals with what the text talks about and involves interpreting the underlying meaning of the text. The analysis was conducted at both the manifest (categories) and latent (theme) levels and was conducted without a precondition (cf. Graneheim et al., 2017).

The analysis started with several readings of the interview texts to obtain a sense of the whole content of women's experiences of living with COPD stage III or IV (I) and those of their close relatives (II). In the next step, meaning units were identified as guided by the aim of the study. A meaning unit is a cluster of words or statements that relates to the content with the same central meaning (Granheim & Lundman, 2004). The meaning units were then condensed. The condensed meaning units are labelled with codes. A code is a label for a meaning unit and should be understood in relation to the context. The codes are then sorted into categories based on similarities and differences in content. Abstraction and sorting are an important part of the analysis process and involve making interpretations and descriptions on a higher logical level. A category is defined as a group of content that shares mutuality and are internally homogenous and externally heterogenous. A theme can have several meanings and is a way to link the underlying meanings together in categories (Granheim & Lundman, 2004). The categories were compared, and a theme was identified, based on threads of meaning that repeatedly appeared in category after category (cf. Baxter, 1991 p. 250). The transcript was then reread to refine and verify the theme with three categories (I) and the theme with five categories (II).

Ethical considerations

This licentiate thesis (I, II) was conducted and guided by the standards set out by the Declaration of Helsinki (World Medical Association, 2018) and was approved by the Swedish Ethical Review Authority (Dnr. 2020-00085). Participation was voluntary, and participants were guaranteed confidentiality and an anonymous presentation of the findings. They were informed that they could withdraw at any time without explanation. To meet possible needs if the interviews caused emotional reactions, participants were given contact information about how to proceed. To my knowledge, no participant requested these contacts. All participants were informed that the interview recordings and transcripts would be kept in a locked filing cabinet at Mid Sweden University according to local regulations. According to Polit and Beck (2021), confidentiality means that no information from the participants, or collected data, will be accessible to no one other than the researcher. There was no dependent relationship between the participants and the researchers. Before the start of the interviews (I, II), the participants were informed verbally once again by AE about the aim and implementation of the study as well as their rights, and they were given time for questions before and after the interviews.

Findings

The findings in this licentiate thesis (I, II) are presented separately. An overview of the themes and categories are presented in Table 3.

Table 3. *Overview of themes and categories (I, II).*

Paper	Themes	Categories
I	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
II	Being flexible to accommodate the women's needs	Desiring to help by being available Reducing isolation and using digital media Experiencing a stressful everyday life Living in a gradually changed and restricted normality Lacking support

Paper I

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

Women with COPD stage III or IV experienced breathlessness that alternated between ever-present and severe but could be stabilized by restoring strength. This severely restricted their everyday life and required detailed planning based on daily health variations. The findings are presented in the overarching theme of *stabilizing an ever-present breathlessness by restoring strength*, which contains three categories.

The category *managing a restricted everyday life as an expert of their illness* was related to how women with COPD stage III or IV had to plan their basic needs of everyday life according to their breathing rhythm. The participants used their own expertise regarding their illness to manage everyday chores. They described having problems managing their personal hygiene or housekeeping, reporting that eating or preparing meals could be an obstacle and could trigger severe breathlessness. Physical activity was challenging because their lungs felt stiff, especially in the morning. Participants said that different weather conditions could affect breathing. Some women with COPD stage III or IV described mood alterations and feelings of grief due to their loss of abilities. When experiencing deterioration, women with COPD stage III or IV said they managed by using breathing techniques and evaluating the need for corticosteroids or antibiotics. Participants reported that physical aids were valuable in managing everyday life, enabling them to participate in activities and helping to prevent isolation. The women described how limited energy contributed to isolation. Amusements at home included solving puzzles or watching TV. Women with COPD stage III or IV described the value of physical activity in stabilizing their illness. If their body had enough strength, they could do housework or visit a friend. Having a positive outlook on life helped to manage doing things they wanted to and sometimes just to endure. Participants talked about trying to live more in the present and accepting their illness.

The category *being afraid of contracting infections leading to suffocation and suffering* was related to participants' fear of being affected by infections, as an infection could potentially be fatal. The participants shared that they had incorporated social distancing and isolation as measures in their everyday lives. Some women described how they had dismissed home care out of fear of the pandemic outbreak, saying that they had terrifying thoughts about death. They were certain that a COVID-19 infection would cause their death. The women said that if they were faced with a life-threatening situation, they would want to avoid suffering, as their everyday life consists of an ever-present breathlessness. Few participants had previously talked about death with their close relatives, but recently this topic had become more urgent due to the pandemic.

The category *importance of continuous help and support from significant others and digital media* was related to the women's description of how relationships with significant others (i.e., family members, medical professionals and others) enriched their lives and was of great importance to their help and support. Social media and discussion forums were supportive in terms of exchanging advice regarding medicines; challenging topics could also be discussed in this way, such as mortality in case of deterioration and care in other parts of Sweden. Accompaniment was described as important, whether face-to-face or, during the COVID-19 pandemic, digitally or by phone. Some women with COPD stage III or IV talked about things they could not do themselves due to their illness, and those who lived with spouses often had to rely on their spouses to perform many of the women's everyday life chores. There were also women with COPD stage III or IV who lived alone and had close friends as a prominent support source. In case of a need for contact with healthcare professionals, most of the women with COPD stage III or IV described encounters with in-patient care professionals in positive tones. A few women described care encounters in negative terms, in particular with physicians around the issue of smoking cessation efforts. Participants shared that close

relatives viewed COPD as a self-inflicted disease linked to previous smoking. Further, the participants described experiences of labelling and being compared to persons living with HIV or to addicts by other people in society, who generally seem to regard the disease as shameful and unlovely. There were many women with COPD stage III or IV who said that they lacked continuity with healthcare professionals. Because they viewed themselves as experts when it came to stabilizing an ever-present breathlessness by restoring strength, participants were afraid that they would not receive correct care or were reluctant to listen to advice. To feel safe, women wanted improvements in the continuity of care, and they promoted individualized care. They wanted to be seen as a whole person, rather than feel like their physicians were focusing on medical matters alone.

Paper II

Experiences from close relatives of women with stage III or IV chronic obstructive pulmonary disease: A qualitative study

The findings showed one overarching theme—*being flexible to accommodate the women's needs*—which meant that close relatives took on a suitable rhythm to synchronize and adjust with the women's current health. The theme consists of five categories.

The category *desiring to help by being available* was related to participants' perception of the importance of being available to aid the women with COPD and to their stated desire to help and ease the women's burden. Easing their burden was described in terms of providing practical support and doing several other chores such as housework. To help maintain the women's abilities, close relatives described tasking the women with a simple chore every day. The COVID-19 pandemic forced the participants to rethink the way they gave practical support, trying to avoid infecting the women. They started using digital services. Close relatives prioritized being available in non-physical ways such as using Skype and described their flexibility in adapting to

the women's needs. This flexible support incorporated emotional support and being on stand-by due to the women's sensitivity to the rapid onset of symptom flare-ups or infections.

The category *reducing isolation and using digital media* was related to participants' active efforts to prevent their relative from experiencing isolation, by focusing on simplicities: just being together. Participants said that they focused on the possibility of trying to continue activities they used to do together and that by being present, they could help to decide what activity was possible to perform, and in what way. After the outbreak of the COVID-19 pandemic, close relatives reported that their constant worries for the women increased. Therefore, using digital and social media became even more important, enabling participants to communicate, prevent isolation, and socialize with their relative with COPD stage III or IV.

The category *experiencing a stressful everyday life* was related to how painful it was for participants to witness their relative's panic caused by an ever-present breathlessness. Close relatives said that this stress could cause similar feelings in their own bodies, describing the woman's affliction as a shared burden. Worries and stressful emotions could wash over both of them. Living in this painful atmosphere caused by the women's illness meant that close relatives had to tip-toe and maintain a flexible mindset regarding the women's needs, depending on her current health. Close relatives expressed that the COVID-19 outbreak was even more stressful because it reinforced the threat to women with COPD stage III or IV; close relatives expressed their fear that their relative would be infected by COVID-19 and not survive.

The category *living in a gradually changed and restricted normality* was related to those close relatives who lived as a couple with a woman with COPD stage III or IV. They described how they did not notice that the woman's illness was deteriorating gradually because they got used to the woman's ever-present breathlessness and that they were living

in a gradually, yet controlled everyday life for close relatives. Participants' flexibility helped them remain calm when interacting with their relative, and in some ways the relative's difficulties became mutual. The couple's social life was controlled by the woman's limited energy, and in their present situation, they had to accept a more sedentary and less social life. Another challenging insight among couples was that they described changed intimacy. The reality that they were living in an unnoticed controlled normality as a close relative of a woman with COPD stage III or IV did not become apparent until they realized the severity of the woman's poor health. The COVID-19 pandemic dictated an even more controlled everyday life for the close relatives. They expressed that they were constantly considering the risk of becoming infected and transmitting the virus to their relative. Thus, participants expressed uncertainty and unpredictability about the progression of their relative's disease.

The category *lacking support* was related to close relatives' lack of information, knowledge, and resources from healthcare professionals, authorities, and society. Consequently, close relatives talked about experiences of that their women with COPD, were being treated unfairly by people and institutions that should have been more supportive. In addition, close relatives felt a need for basic assistance, such as resources, participation, and continuity. Examples of resources that they felt they lacked were time for shared decision-making, continuous multi-professional support for their relative with COPD stage III or IV, and a contact nurse to offer advice and clinical follow-up. Participants described such resources as a necessity to compensate for an illness that had caused physical, psychological, and social losses. The close relatives shared that if they could provide the support that they thought was lacking from healthcare professionals, they themselves could contribute to the women's needs and balance their own stress over the concerns of everyday life.

Discussion

The overall aim for this licentiate thesis was to describe the experiences of women living with COPD stage III or IV and the experiences as a close relative. The findings show that ever-present breathlessness restricted women's activities due to a lack of energy and that they had to live with a breathing and a body which they had to await for. Stabilizing an ever-present breathlessness by restoring strength helped women with COPD stage III or IV manage everyday life and adapt to their limited abilities and energy. This restoration required detailed planning and a good knowledge of their breathing and body. They were afraid of contracting life-threatening infections that could cause suffering, especially COVID-19. Fear led to isolation, and digital media were described as an important means of communication to break isolation (I). The findings show that close relatives were of major importance to women with COPD stage III or IV in their everyday life, in terms of being flexible to accommodate the women's needs. Close relatives were flexible, available, and on stand-by (II). Women with COPD stage III or IV experienced the COVID-19 pandemic as a reinforced threat (I), and close relatives raised awareness of the women's vulnerability to potentially life-threatening infections (II). Close relatives tried to avoid these threats by using digital media instead of meeting in person, or avoid contacts. As a consequence, close relatives lived a more sedentary everyday life which had become their normality (II).

The findings are related to Katie Eriksson's research about suffering, where the opposite of health is not illness but suffering, if it is bearable. Suffering is a part of health, and health is compatible with enduring suffering, i.e., a person who suffers can experience health at the same time (Eriksson, 2018). The women's experiences of living with COPD stage III or IV can be seen as suffering illness and suffering of care. The experiences of close relatives can be seen as co-lateral suffering. Thus, while there were expressions of suffering, the findings show that both women and their close relatives also experienced health. Further, the

findings are related to suffering and enduring as described by Morse and Carter (1996) and previous research.

For women with COPD stage III or IV, the normal functions of breathing became an ever-present challenge. This ever-present breathlessness and gradual deterioration caused feelings of both grief and loss due to decreased abilities and independence in everyday life. The everyday struggle with breathing and, consequently, a body they had to wait for was challenging. For example, everyday life chores such as preparing meals or eating could trigger severe breathlessness. Also, the physical activity involved in managing personal hygiene was challenging due to their decreasing lung function, especially in the morning (I). This can be seen as what Eriksson (2018) described as suffering of illness as represented by women's living with a deteriorated body.

Even though ever-present breathlessness is painful, women with COPD stage III or IV expressed the importance of managing life by being positive and doing everyday chores. In response to their struggle, they described trying to live more in the present and to accept their illness progression. Women with COPD stage III or IV expressed that when they faced deterioration, they gained control by using breathing techniques and by evaluating the need for corticosteroid or antibiotics (I). They perceived themselves as being the experts of their own illness and that expertise was seen as a tool to control and manage their illness and thereby experience health. According to Eriksson (2018), a sense of control can reduce suffering of illness. Having tools to support health is compatible with enduring suffering, i.e., a person who suffers can experience health at the same time, if the suffering is bearable.

Close relatives expressed that it was painful to see women's daily health affected by COPD stage III or IV as caused by an ever-present breathlessness. They shared that witnessing their close relative panic in the face of severe breathlessness was emotionally stressful and caused similar feelings in their own bodies (II). Hynes et al. (2012)

described the strain of bearing witness to people with COPD. The findings show that close relatives described that living in this painful atmosphere required them to be on their toes, stay flexible, and remain calm while addressing the woman's needs, depending on her current health. This mindset is related to the close relatives' desire to give emotional support and to help by being available. To help, close relatives provided practical support in everyday chores such as housework. They also tried to help women with COPD stage III or IV maintain their abilities and independence, close relatives tasked them with simple chores in their everyday lives. Close relatives expressed that even if the future appeared uncertain and unpredictable, they counted on simplicities in life such as just being together (II). Eriksson (2018) stated that suffering with another person is not the same as one's own suffering. To suffer with another is to be sensitive or compassionate to the other's suffering, and to try to alleviate it.

Chronic obstructive pulmonary disease is an illness that causes a gradual deterioration, and close relatives expressed that they adjusted to women's ever-present breathlessness as a part of their ongoing normality, saying that their deepening insight into their relative's poor health affected their social life and sometimes caused changes in intimacy for couples (II). Research indicates that close relatives to people with other long-term illnesses experienced feelings of loneliness and lack of social contacts (Martin, 2016; Reid & O'Brian, 2021), which suggests that addressing such issues among close relatives of women with COPD stage III or IV could also support the close relatives' health. However, other research has found that close relatives can play an important role in engaging women in activities, thus preventing a completely sedentary life while simultaneously supporting health for both the women and their close relatives (Seamark et al., 2004).

Women with COPD stage III or IV expressed the importance of continuous relationships such as visiting friends, as long as they had enough energy to manage their breathing and body. The findings show

that physical activity and social relationships brought satisfaction and helped the women live with the illness (I). Having the energy to visit a friend can be understood as satisfying, and an expression of health since health is associated with all the positive values in life (Eriksson, 2018).

Women with COPD stage III or IV reported using digital media to exchange knowledge or discuss challenging topics with other people with COPD. In other words, using digital media offered accompaniment (I). This aligns with Ali et al. (2018), who found that people with COPD considered it helpful to share their experiences and listen to other people's thoughts. For close relatives, digital media reduced worries; they expressed that this was a support to reduce isolation for the women as well. Reducing isolation was especially important due to the COVID-19 pandemic (II). Fear of COVID-19 was especially stressful for women with COPD stage III or IV. They were certain that COVID-19 would cause their death if they became infected. Women lived with social distancing and isolation; some even dismissed home care out of fear. However, women with COPD stage III or IV did not fear death itself. They feared suffocation, and their minds were occupied by how to avoid suffering through suffocation (I). Molzahn et al., (2021) stated that people with COPD stage IV were not afraid of death itself but of the scary experiences of shortness of breath. According to Morse and Carter (1996), emotional suffering and enduring is a hovering movement continually going back and forth. People move from enduring to suffering, and when they can acknowledge what is being endured and are emotionally strong, they can accept reality.

Close relatives to women with COPD stage III or IV had constant worries, stress, and fear that their relative would catch an infection or die. This fear worsened due to the COVID-19 pandemic (II). Rapid onset of symptoms, flare-ups or infections obliged close relatives to be on stand-by. Mousing and Sørensen (2021) found that living with the

threat of being infected by COVID-19 affected the everyday life of people with COPD stage II or III, who described the virus as a death threat. According to Morse and Carter (1996), enduring to live is connected to psychologically difficult situations (i.e., COPD stage III or IV), and enduring is an adaptive behavior. Due to the COVID-19 pandemic and the fear of infecting women with COPD stage III or IV, close relatives adjusted their support, for instance by buying groceries online or not chatting face-to-face. The use of digital media became even more important. This enabled close relatives to communicate, socialize, and prevent isolation for women with COPD stage III or IV (II). This is one example of alleviating suffering of illness (Eriksson, 2018).

The findings show that women with COPD stage III or IV felt labeled as if they were compared to people with HIV or addictions. Women with COPD stage III or IV felt having no right to complain, only to accept the consequences of their illness. They generally characterized encounters with healthcare professionals as positive, although some had negative experiences regarding previous smoking cessation efforts. Women with COPD stage III or IV promoted individualized care and wanted to be seen as a whole person in all contacts with healthcare professionals (I). According to Eriksson (2018), this can be seen as an expression of suffering of care, where the dignity of a person is violated. Further, Eriksson (2002) states that suffering and health are interrelated and that conversations about suffering could be crucial for maintaining relationships with oneself and others. Such conversations could arise if healthcare professionals show people authentic interest and affirm them as a person in their suffering. Eriksson (2018) states that such care could result in alleviated suffering. Close relatives expressed that they had witnessed unfair treatment of women with COPD stage III or IV in healthcare encounters. In line with Eriksson (2018), this is an expression of suffering of care, where the caring dimension is missing.

Women with COPD stage III or IV and their close relatives expressed that they lacked continuity, participation, and support from healthcare (I, II). According to Eriksson (2018), being a person without rights can be seen as a type of suffering of care. Previous research defines continuity of care in terms of information exchange, management, interpersonal relationships and sustained continuity of care that improves quality of life for people with long-term illness (Romaine et al., 2014; van Walraven et al., 2010). Knowledge of people's experiences of living with long-term illness is very important for healthcare professionals to be able to support increased well-being (cf. Stridsman et al., 2014).

Methodological considerations

The quality criteria often used in qualitative research to evaluate trustworthiness are credibility, dependability, confirmability, transferability, and authenticity (Lincoln & Guba, 1985). Credibility means confidence in the interpretation of the data. In accordance with the aim of the two papers—which was to describe the experiences of women living with COPD stage III or IV and the experiences of their close relatives—individual interviews were the most suitable method. To maintain credibility, the data collection, the findings, and the interpretation of the findings were presented as clearly and carefully as possible. To demonstrate credibility, there are examples of the analysis process with quotations in Papers I and II. Credibility in analysis is also a question of how to assess similarities within and differences between categories. One way to approach this is to display representative quotes from the transcribed text (Graneheim & Lundman, 2004). The interviews were initially not planned to be conducted by telephone, but due to social distancing recommendations during the pandemic, all interviews were performed by telephone as this method made it possible to get access to all the participants. To accomplish credibility in the analysis, the analysis moved back and forth between the interview text, meaning units, condensed meaning units, codes, categories, and theme until an agreement was reached. The findings were presented in themes (cf. Baxter, 1991, p. 250), and according to Sandelowski (2000), in qualitative descriptive studies researchers will agree more readily on the same findings even if they do not choose to present the findings in the same way. Trustworthiness is strengthened if the findings are presented in a way that allows the reader to judge the interpretations of the result (Graneheim & Lundman, 2004).

Trustworthiness also involves the criterion of dependability, which refers to stability of data over time (Lincoln & Guba, 1985). One way to achieve dependability was continuous discussions in research team. A pilot interview was conducted to test the interview guide in study I,

and the testing did not lead to any changes. The first interview in study II was considered a pilot test, and no reason was found for changes.

Confirmability refers to the objectivity of the data (Lincoln & Guba, 1985). To achieve confirmability, a purposive sample was used based on inclusion criteria. Fifty invitation letters were sent to women who fulfilled the inclusion criteria. According to the ethical approval, participants do not have to declare that they were not participating in the invitation. In qualitative research, drop-out analyses are not commonly used. The sample was based on a model of sample size in the qualitative selection and information power (Malterud, 2016). Fifteen women were recruited who were willing to share their experiences. This number was considered sufficient and allowed studying various women's experiences of their everyday life with COPD stage III or IV, which can be understood as replication and with a heterogony sample (Polit & Beck, 2021). According to Polit and Beck (2021), this contributes to a richer variation of the phenomena under study. The sample in this study varied with regard to age, whether they lived alone or with a spouse, rural versus urban residence, education level and progression in their disease. In the study presented in Paper II, the sample size was rather small. The shortest interview lasted 32 minutes but had rich content. However, the sample size of close relatives was considered to be large enough because it contributed richness and depth to the analysis. The sample size in qualitative research should be large enough to achieve variations in experiences, and it should include rich data while remaining small enough to permit a deep analysis of the data (Sandelowski, 2000). In both papers, confirmability was further sought through reflecting the participants' voices in the findings. The two studies in this licentiate thesis were planned before the COVID-19 pandemic, but the interviews were performed accordingly by telephone, during the outbreak in Sweden (March-May 2020), which may influence the gathered data. One possible effect was that the women with COPD stage III or IV talked about fearing infections, even though the interview questions did not specifically mention the pandemic. Women and their close relatives spontaneously brought up this topic.

Nonetheless, data was gathered regarding the everyday life of women with COPD stage III or IV and their close relatives in a unique situation and in a way not previously described.

Transferability is another aspect of trustworthiness (Lincoln and Guba, 1985). The findings in this licentiate thesis are specific to women with COPD stage III or IV and their close relatives. Thus, the findings cannot be generalized, although they may be transferred to other similar diagnoses and contexts (Polit & Beck, 2021). Reflexivity comprises the researcher's background, experience, education, and the way the researcher engages in data collection and analysis (Brinkman & Kvale, 2015). During interviews, the participants were given the opportunity to clarify their answers and messages with questions. The strategy for handling possible influence on data collection, analysis, and interpretation was to have continuous discussions with the research team and fellow students. Further, the context and participants were described as thoroughly as possible while retaining anonymity and confidentiality.

Concluding remarks

Research is lacking with a focus on the experiences of women with COPD stage III or IV and their close relatives. The findings of this licentiate thesis show that women with COPD stage III or IV and their close relatives experience both health and suffering in their everyday lives. Despite the severity and unpredictability of the women's illness and the close relatives' everyday life being continually on stand-by, women with COPD have learned how to live with the illness in everyday life by becoming the experts in their own illness. Women with COPD stage III or IV manage everyday suffering and ever-present breathlessness through detailed planning, self-isolation, and support from their close relatives. The use of digital media was highlighted as supportive, especially during the COVID-19 pandemic. Participants also described a lack of continuity and support from healthcare professionals.

The knowledge gained from this licentiate thesis can be used for clinical implications in terms of possibly increasing digital care for women with COPD stage III or IV. The use of digital care could alleviate suffering for women and their close relatives, enabling safe, accessible, and individual support. Further, digital care strengthens the prerequisite for developing continuous healthcare relations. Participants in this licentiate thesis consistently expressed their desire for continuity in healthcare.

A future vision for care would involve multi-professional collaborations for women with COPD stage III or IV and their close relatives. The findings regarding women's experience of being labelled because of their COPD illness could indicate a need to raise awareness of this stigma among healthcare professionals who meet with women with COPD stage III or IV. It seems that close relatives' health is at risk due to their gradually increasing sedentary time, an issue which has not previously been addressed.

References

- Ahlström, G. (2007). Experiences of loss and chronic sorrow in persons with severe chronic illness. *Journal of Clinical Nursing*, 16(3a), 76-83. <https://doi.org/10.1111/j.1365-2702.2006.01580.x>
- Ali, L., Fors A., & Ekman, I. (2018). Need of support in people with chronic obstructive pulmonary disease. *Journal of Clinical Nursing*, 27(5-6), 1089-1096. <https://doi.org/10.1111/jocn.14170>
- Ali, L., Wallström, S., Ekman, I., Swedberg, K., & Fors, A. (2021). Effects of person-centered care via telephone on self-efficacy in patients with chronic obstructive pulmonary disease: Subgroup analysis of a randomized controlled trial. *Nursing Open*, 8(2), 927– 935. <https://doi.org/doi:10.1002/nop2.701>
- Andersen, I. C., Thomsen, T. G., Bruun, P., Bødtger, U., & Hounsgaard, L. (2018). Between hope and hopelessness: COPD patients' and their family members' experiences of interacting with healthcare providers – A qualitative longitudinal study. *Scandinavian Journal of Caring Sciences*, 32(3), 1197-1206. <https://doi.org/10.1111/scs.12565>
- Andrade, L., Caraveo-Anduaga, J. J., Berglund, P., Bijl, R. V., De Graaf, R., Vollebergh, W., Dragomirecka, E., Kohn, R., Keller, M., Kessler, R. C., Kawakami, N., Kiliç, C., Offord, D., Ustun, T. B., & Wittchen, H. (2003). The epidemiology of major depressive episodes: results from the international consortium of psychiatric epidemiology (ICPE) Surveys. *International Journal of Methods in Psychiatric Research*, 12(1), 3–21. <https://doi.org/10.1002/mpr>.
- Aryal, S., Diaz-Guzman, E., & Mannino, D. M. (2014). Influence of sex on chronic obstructive pulmonary disease risk and treatment outcomes. *International Journal of Chronic Obstructive Pulmonary Disease*, 9(1), 1145–1154. <https://doi.org/10.2147/COPD.S54476>
- Axelsson Fisk, S. (2021) 'Society inhaled. Social epidemiology of COPD', [Doctoral dissertation], Lund University.

- Backman, H., Eriksson, B., Rönmark, E., Hedman, L., Stridsman, C., Jansson, S. A., Lindberg, A., & Lundbäck, B. (2016). Decreased prevalence of moderate to severe COPD over 15 years in northern Sweden. *Respiratory Medicine*, 114, 103-110. <https://doi.org/10.1016/j.rmed.2016.03.013>
- Backman, H., Vanfleteren, L., Lindberg, A., Ekerljung, L., Stridsman, C., Axelsson, M., Nilsson, U., Nwaru, B. I., Sawalha, S., Eriksson, B., Hedman, L., Rådinger, M., Jansson, S. A., Ullman, A., Kankaanranta, H., Lötval, J., Rönmark, E., & Lundbäck, B. (2020). Decreased COPD prevalence in Sweden after decades of decrease in smoking. *Respiratory Research*, 21(283), 1-12. <https://doi.org/10.1186/s12931-020-01536-4>
- Badr, H., Federman, A. D., Wolf, M., Revenson, T. A., & Wisnivesky, J. P. (2017). Depression in individuals with chronic obstructive pulmonary disease and their informal caregivers. *Aging & Mental Health*, 21(9), 975–982. <https://doi.org/10.1080/13607863.2016>.
- Bagnasco, A., Rosa, F., Dasso, N., Aleo, G., Catania, G., Zanini, M., Rocco, G., Turci, C., Ghirotto, L., Hayter, M., & Sasso, L. (2021). Caring for patients at home after acute exacerbation of chronic obstructive pulmonary disease: A phenomenological study of family caregivers' experiences. *Journal of Clinical Nursing*, 30(15-16), 2246–2257. <https://doi.org/10.1111/jocn.15613>
- Bailey, P. H. (2004). The dyspnea-anxiety-dyspnea cycle--COPD patients' stories of breathlessness: "It's scary /when you can't breathe". *Qualitative Health Research*, 14(6), 760-778. <https://doi.org/10.1177/1049732304265973>
- Baxter, L. A. (1991). *Content analysis: Toward the synthesis of quantitative and qualitative methods*. In B. Montgomery & S. Duck (Eds.), *Studying interpersonal interaction* (pp.239-254). The Guilford Press.
- Brinkman, S., & Kvale, S. (2015). *InterViews. Learning the craft of qualitative research interviewing*, (3rd ed.) Thousand Oaks, CA: Sage.

- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-195. <https://doi.org/10.1111/1467-9566.ep10491512>
- Corbin, J. M., & Strauss, A. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. *Research in the Sociology of Health Care*, 9, 249-281.
- Corbin, J. M. (2003). The body in health and illness. *Qualitative Health Research*, 13(2), 256–267. <https://doi.org/10.1177/1049732302239603>
- Cruz, J., Marques, A., & Figueiredo, D. (2017). Impacts of COPD on family carers and supportive interventions: a narrative review. *Health and Social Care in the Community*, 25, 11-25. <https://doi.org/10.1111/hsc.12292>
- Dahlberg, K., Segesten, K. (2010). *Hälsa och vårdande i teori och praktik* (Health and caring in theory and praxis). Natur & Kultur.
- Dahlberg, K., Dahlberg, H., & Nyström., N. (2008). *Reflective Lifeworld research*. Studentlitteratur.
- Doyal, L. (1995). *What makes women sick*. Macmillan.
- Ek, K., Andershed, B., Sahlberg-Blom, E., & Ternestedt, B. M (2015). "The unpredictable death" –The last year of life for patients with advanced COPD: Relatives' stories. *Palliative and Supportive Care*, 13(5), 1213-1222. <https://doi.org/10.1017/S1478951514001151>
- Ek, K., & Ternestedt, B. M. (2008). Living with chronic obstructive pulmonary disease at the end of life: a phenomenological study. *Journal of advanced nursing*, 62 (4), 470–478. <https://doi.org/10.1111/j.1365-2648.2008.04611.x>
- Eriksson K. (2002). Caring science in a new key. *Nursing science quarterly*, 15(1), 61–65. <https://doi.org/10.1177/089431840201500110>
- Eriksson, K (2014) *Vårdprocessen* [The caring process]. Liber.
- Eriksson, K. (2018). *Vårdvetenskap Vetenskapen om vårdandet, om det tidlösa i tiden*. Liber.

- Eriksson, E., Wejåker, M., Danhard, A., Nilsson, A., & Kristofferzon, M. L. (2019). Living with a spouse with chronic illness – the challenge of balancing demands and resources. *BMC Public Health*, 19(422), 1-9. <https://doi.org/10.1186/s12889-019-6800-7>
- European Commission. (2014). *Population ageing in Europe: Facts, implications and policies*. Retrieved from <https://op.europa.eu/en/publication-detail/-/publication/1e7549b4-2333-413b-972c-f9f1bc70d4cf/language-en>
- Farquhar, M. (2018). Assessing carer needs in chronic obstructive pulmonary disease. *Chronic Respiratory Disease*, 15(1), 26–35. <https://doi.org/10.1177/1479972317719086>
- Fawcett, J. (2005). Criteria for evaluation of theory. *Nursing Science Quarterly*, 18(2), 131–135. <https://doi.org/10.1177/0894318405274823>
- Figueiredo, D., Gabriel, R., Jácome, C., Cruz, J., & Marques, A. (2014). Caring for relatives with chronic obstructive pulmonary disease: How does the disease severity impact on family carers? *Aging and Mental Health*, 18(3), 385-393. <https://doi.org/10.1080/13607863.2013.837146>
- Fraser, D. D., Kee, C. C., & Minick, P. (2006). Living with chronic obstructive pulmonary disease: insiders' perspectives. *Journal of Advanced Nursing*, 55, 550-558. <https://doi.org/10.1111/j.1365-2648.2006.03946.x>
- Fusi-Schmidhauser, T., Froggatt, K., & Preston, N. (2020). Living with advanced chronic obstructive pulmonary disease: A Qualitative interview study with patients and informal carers. *COPD: Journal of Chronic Obstructive Pulmonary Disease*, 17(4), 410–418. <https://doi.org/10.1080/15412555.2020.1782867>
- Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Halpin, D., Ruse, C., & Seamark, D. (2010). Exploring the care needs of patients with advanced COPD: an overview of the literature. *Respiratory Medicine*, 104(2), 159–165. <https://doi.org/10.1016/j.rmed.2009.09.007>

- Global Initiative for Chronic Obstructive Lung Disease (GOLD) (2021). Agusti, A. *Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease*. Retrieved from: http://www.goldCOPD.org/uploads/users/files/GOLD_Report_2021sept17.pdf
- Gore, J. M., Brophy, C. J., & Greenstone, M. A. (2000). How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*, 55(12), 1000–1006. <https://doi.org/10.1136/thorax.55.12.1000>
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Graneheim, U. H., Lindgren, B-M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, 56, 29-34. <https://doi.org/10.1016/j.nedt.2017.06.002>
- Grigsby, M., Siddharthan, T., Chowdhury, M. A., Siddiquee, A., Rubinstein, A., Sobrino, E., Miranda, J. J., Bernabe-Ortiz, A., Alam, D., & Checkley, W. (2016). Socioeconomic status and COPD among low- and middle-income countries. *International Journal of Chronic Obstructive Pulmonary Disease*, 11(1), 2497–2507. <https://doi.org/10.2147/COPD.S111145>
- Habraken, J. M., Pols, J., Bindels, P. J., & Willems, D. L. (2008). The silence of patients with end-stage COPD: a qualitative study. *The British Journal of General Practice : the Journal of the Royal College of General Practitioners*, 58(557), 844–849. <https://doi.org/10.3399/bjgp08X376186>
- Hammarström, A. (2005). *Genusperspektiv på medicinen [Elektronisk resurs] två decenniers utveckling av medvetenheten om kön och genus inom medicinsk forskning och praktik*. (2. uppl.) Stockholm: Högskoleverket i samarbete med Nationella sekretariatet för genusforskning.

- Huisman, M., Kunst, A. E., & Mackenbach, J. P. (2005). Educational inequalities in smoking among men and women aged 16 years and older in 11 European countries. *Tobacco Control, 14*(2), 106–113. <https://doi.org/10.1136/tc.2004.008573>
- Hynes, G., Stokes, A., & McCarron, M. (2012). Informal care-giving in advanced chronic obstructive pulmonary disease: Lay knowledge and experience. *Journal of Clinical Nursing, 21*(7-8), 1068-1077. <https://doi.org/10.1111/j.1365-2702.2011.03944.x>
- Jácome, C., Figueiredo, D., Gabriel, R., Cruz, J., & Marques, A. (2014). Predicting anxiety and depression among family carers of people with chronic obstructive pulmonary disease. *International Psychogeriatrics, 26*(7), 1191-1199. <https://doi.org/10.1017/S1041610214000337>
- Johansson, H., Berterö, C., Berg, K., & Jonasson, L. L. (2019). To live a life with COPD - the consequences of symptom burden. *International Journal of Chronic Obstructive Pulmonary Disease, 14*, 905–909. <https://doi.org/10.2147/COPD.S192280>
- Jonsdottir, R., & Jonsdottir, H. (2007). The experience of women with advanced chronic obstructive pulmonary disease of repeatedly relapsing to smoking. *Scandinavian Journal of Caring Sciences, 21*(3), 297-304. <https://doi.org/10.1111/j.1471-6712.2007.00472.x>
- Jumisko, E., Lexell, J., & Söderberg, S. (2007). Living with moderate or severe traumatic brain injury: the meaning of family members' experiences. *Journal of Family Nursing, 13*(3), 353–369. <https://doi.org/10.1177/1074840707303842>
- Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing, 72*(12), 2954–2965. <https://doi.org/10.1111/jan.13031>

- Kanervisto, M., Kaistila, T., & Paavilainen, E. (2007). Severe chronic obstructive pulmonary disease in a family's everyday life in Finland: Perceptions of people with chronic obstructive pulmonary disease and their spouses. *Nursing and Health Sciences*, 9(1), 47. <https://doi.org/10.1111/j.1442-2018.2007.00303.x>
- Kokturk, N., Kilic, H., Baha, A., Lee, S. D., & Jones, P. W. (2016). Sex difference in chronic obstructive lung disease. Does it matter? A concise review. *Journal of Chronic Obstructive Pulmonary Disease*, 13(6), 799-806. <https://doi.org/10.1080/15412555.2016.1199666>
- Kralik, D. (2002). The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39(2), 146-154. <https://doi.org/10.1046/j.1365-2648.2000.02254.x>
- Kralik, D., Brown, M., & Koch, T. (2001). Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing*, 33(5), 594-602. <https://doi.org/10.1046/j.1365-2648.2001.01704.x>
- Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: Taking action to create order. *Journal of Clinical Nursing*, 13(2), 259-267. <https://doi.org/10.1046/j.1365-2702.2003.00826.x>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE Publications.
- Lindqvist, G., Albin, B., Heikkilä, K., & Hjelm, K. (2013b). Conceptions of daily life in women living with a man suffering from chronic obstructive pulmonary disease. *Primary Health Care Research & Development*, 14(1), 40-51. <https://doi.org/10.1017/S146342361200031X>

- Lindqvist, G., Heikkilä, K., Albin, B., & Hjelm, K. (2013a). Conceptions of daily life in men living with a woman suffering from chronic obstructive pulmonary disease. *Primary Health Care Research & Development*, 14(2), 140-150. <https://doi.org/10.1017/S1463423612000394>
- Lisspers, K., Larsson, K., Janson, C., Ställberg, B., Tsiligianni, I., Gutzwiller, F. S., Mezzi, K., Bjerregaard, B. K., Jorgensen, L., & Johansson, G. (2019). Gender differences among Swedish COPD patients: Results from the ARCTIC, a real-world retrospective cohort study. *npj Primary Care Respiratory Medicine*, 29(45), 1-8 <https://doi.org/10.1038/s41533-019-0157-3>
- Malterud, K. (1987). Illness and disease in female patients: II. A study of consultation techniques designed to improve the exploration of illness in general practice, *Scandinavian Journal of Primary Health Care*, 5(4), 211-216. <https://doi.org/10.3109/02813438709018097>
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- Marques, A., Jácome, C., Cruz, J., Gabriel, R., Brooks, D., & Figueiredo, D. (2015). Family-based psychosocial support and education as part of pulmonary rehabilitation in COPD: A randomized controlled trial. *Chest*, 147(3), 662-672. <https://doi.org/10.1378/chest.14-1488>
- Martin, S. C. (2016). Relational issues within couples coping with parkinson's Disease: Implications and ideas for family-focused care. *Journal of Family Nursing*, 22(2), 224–251. <https://doi.org/10.1177/1074840716640605>
- Miravittles, M., Peña-Longobardo, L. M., Oliva-Moreno, J., & Hidalgo-Vega, Á. (2015). Caregivers' burden in patients with COPD. *International Journal of Chronic Obstructive Pulmonary Disease*, 10(1), 347–356. <https://doi.org/10.2147/COPD.S76091>

- Miravittles, M., & Ribera A. (2017). Understanding the impact of symptoms on the burden of COPD. *Respiratory Research*, 18(1), 63–67. <https://doi.org/10.1186/s12931-017-0548-3>
- Molzahn, A. E., Shields, L., Antonio, M., Bruce, A., Schick-Makaroff, K., & Wiebe, R. (2021). Ten minutes to midnight: a narrative inquiry of people living with dying with advanced copd and their family members. *International Journal of Qualitative Studies on Health and Well-being*, 16(1), 1-10 <https://doi.org/10.1080/17482631.2021.1893146>
- Morse, J. M., & Carter, B. (1996). The essence of enduring and expressions of suffering: the reformulation of self. *Scholarly Inquiry for Nursing Practice*, 10(1), 43–74.
- Morse, J. M. (2018). Theoretical coalescence: A method to develop qualitative theory: The example of enduring. *Nursing Research*, 67(2), 177–187. <https://doi.org/10.1097/NNR.0000000000000263>
- Morse, J. M., & Johnson, J. L. (1991). *The illness experience: Dimensions of suffering*. Sage Publications.
- Mousing, C. A., & Sørensen, D. (2021). Living with the risk of being infected: COPD patients' experiences during the coronavirus pandemic. *Journal of Clinical Nursing*, 30(11-12), 1719–1729. <https://doi.org/10.1111/jocn.15727>
- Musselwhite, K., Cuff, L., McGregor, L., & King, K. M. (2007). The telephone interview is an effective method of data collection in clinical nursing research: a discussion paper. *International Journal of Nursing Studies*, 44(6), 1064–1070. <https://doi.org/10.1016/j.ijnurstu.2006.05.014>
- Nakken, N., Janssen, D. J., van den Bogaart, E. H., Wouters, E. F., Franssen, F. M., Vercoulen, J. H., & Spruit, M. A. (2015). Informal caregivers of patients with COPD: Home sweet home? *European Respiratory Review*, 24(137), 498-504. <https://doi.org/10.1183/16000617.00010114>

- Nilsson, C., Lindberg, B., Skär, L., & Söderberg, S. (2016). Meanings of balance for people with long-term illnesses. *British Journal of Community Nursing*, 21(11), 563-567. <https://doi.org/10.12968/bjcn.2016.21.11.563>
- Nordenfelt, L. (1987) *On the nature of health*. Springer.
- Nordenfelt L. (2007). The concepts of health and illness revisited. *Medicine, Health Care, and Philosophy*, 10(1), 5–10. <https://doi.org/10.1007/s11019-006-9017-3>
- Nykvist, M., Larsson, E-L., Dahlborg, E., & Lyckhage K. (2014). 'It's about me' – a narrative analysis of female smokers with chronic obstructive pulmonary disease (COPD) and their relationship to smoking. *Scandinavian Journal of Caring Sciences*, 28(2), 373–380. <https://doi.org/10.1111/scs.12068>
- Nätterlund, B. (2001). *Living with muscular dystrophy. Illness experiences, activities of daily living and rehabilitation*. [Doctoral dissertation] Uppsala University.
- O'Neill, E. S. (2002). Illness representations and coping of women with chronic obstructive pulmonary disease: A pilot study. *Heart & Lung*, 31(4), 295–302 <https://doi.org/295-302.0.1067/mhl.2002.123712>
- Osika Friberg, I., Krantz, G., Määttä, S., & Järbrink, K. (2016). Sex differences in health care consumption in Sweden: A register-based cross-sectional study. *Scandinavian Journal of Public Health*, 44(3), 264–273. <https://doi.org/10.1177/1403494815618843>
- Patton, M. Q. (2015). *Qualitative research & evaluation methods : integrating theory and practice*. 4. ed.. ed. SAGE Publications.
- Polit, D. F., & Beck, C. T. (2021). *Nursing research: generating and assessing evidence for nursing practice* (11th ed.). Wolters Kluwer.
- Romaire, M. A., Haber, S. G., Wensky, S. G., & McCall, N. (2014). Primary care and specialty providers: an assessment of continuity of care, utilization, and expenditures. *Medical Care*, 52(12), 1042–1049. <https://doi.org/10.1097/MLR.0000000000000246>

- Reid, B., & O'Brien, L. (in press, 2021). The psychological effects of caring for a family member with dementia. *Nursing Older People*. <https://doi.org/10.7748/nop.2021.e1295>
- Sandelowski, M. (2000). Whatever happened to qualitative description?. *Research in Nursing & Health*, 23(4), 334–340. [https://doi.org/10.1002/1098-240x\(200008\)23:4<334::aid-nur9>3.0.co;2-g](https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g)
- Scherman, M. H., Dahlgren, L. O., & Löwhagen, O. (2002). Refusing to be ill: a longitudinal study of patients' experiences of asthma/allergy. *Disability and Rehabilitation*, 24(6), 297–307. <https://doi.org/10.1080/09638280110087106>
- Seamark, D. A., Blake, S. D., Seamark, C. J., & Halpin, D. M. (2004). Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. *Palliative Medicine*, 18(7), 619–625. <https://doi.org/10.1080/09638280110087106>
- Sigurgeirsdottir, J., Halldorsdottir, S., Arnardottir, R. H., Gudmundsson, G., & Bjornsson, E. H. (2020). Frustrated caring: Family members' experience of motivating COPD patients towards self-management. *International Journal of Chronic Obstructive Pulmonary Disease*, 15, 2953–2965. <https://doi.org/10.2147/COPD.S273903>
- Siltanen, H., Jylhä, V., Holopainen, A., & Paavilainen, E. (2019). Family members' experiences and expectations of self-management counseling while caring for a person with chronic obstructive pulmonary disease: a systematic review of qualitative evidence. *JBISRIR-D-19-00056*. *JBISRIR-D-19-00056*, 17(11), 2214–2247. <https://doi.org/10.11124/IBISRIR-D-19-00056>
- Spence, A., Hasson, F., Waldron, M., Kernohan, G., McLaughlin, D., Cochrane, B., & Watson, B. (2008). Active carers: living with chronic obstructive pulmonary disease. *International Journal of Palliative Nursing*, 14(8), 368–372. <https://doi.org/10.12968/ijpn.2008.14.8.30771>

- Statistics Sweden. Population statistics. (2021). Retrieved from: <https://www.scb.se/en/finding-statistics/statistics-by-subject-area/population/population-composition/population-statistics/>
- Steindal, S. A., Österlind, J., Halvorsen, K., Schjelderup, T., Kive, E., Sørbye, L. W., & Dihle, A. (2017). A qualitative study of women's experiences of living with COPD. *Nursing Open*, 4(4), 200–208. <https://doi.org/10.1002/nop2.86>
- Strang, S., Ekberg-Jansson, A., & Henoeh, I. (2014). Experience of anxiety among patients with severe COPD: A qualitative, in-depth interview study. *Palliative & Supportive Care*, 12(6), 465–472. <https://doi.org/10.1017/S1478951513000369>
- Stridsman, C., Lindberg, A., & Skär, L. (2014). Fatigue in chronic obstructive pulmonary disease: a qualitative study of people's experiences. *Scandinavian Journal of Caring Sciences*, 28(1), 130–138. <https://doi.org/10.1111/scs.12033>
- Stridsman, C., Zingmark, K., Lindberg, A., & Skär, L. (2015). Creating a balance between breathing and viability: experiences of well-being when living with chronic obstructive pulmonary disease. *Primary Health Care Research & Development*, 16(1), 42–52. <https://doi.org/10.1017/S1463423614000048>
- Ställberg, B., Janson, C., Johansson, G., Larsson, K., Stratelis, G., Telg, G., & Lisspers, K. H. (2014). Management, morbidity and mortality of COPD during an 11-year period: an observational retrospective epidemiological register study in Sweden (PATHOS). *Primary Care Respiratory Journal*, 23(1), 38–45. <https://doi.org/10.4104/pcrj.2013.00106>
- Sundh, J., & Ekström, M. (2016). Persistent disabling breathlessness in chronic obstructive pulmonary disease. *International Journal of Chronic Obstructive Pulmonary Disease*, 11(1), 2805–2812. <https://doi.org/10.2147/COPD.S119992>

- Söderberg, S., Strand, M., Haapala, M., & Lundman, B. (2003). Living with a woman with fibromyalgia from the perspective of the husband. *Journal of Advanced Nursing*, 42(2), 143–150. <https://doi.org/10.1046/j.1365-2648.2003.02597.x>
- Toombs, S. K. (1992). *The meaning of illness: A phenomenological account of the different perspectives of physician and patient*. Springer.
- Toombs, S. K. (1995). Sufficient unto the day. In Toombs, S. K., Barnard, D., & Carson, R. A. (Eds.), *Chronic Illness: From Experience to Policy* (pp. 1-23). Indiana University Press.
- de Torres, J. P., Casanova, C., Montejo de Garcini, A., Aguirre-Jaime, A., & Celli, B. R. (2007). Gender and respiratory factors associated with dyspnea in chronic obstructive pulmonary disease. *Respiratory Research*, 8(18), 1-7. <https://doi.org/10.1186/1465-9921-8-18>
- de Torres, J. P., Casanova, C., Hernández, C., Abreu, J., Aguirre-Jaime, A., & Celli, B. R. (2005). Gender and COPD in patients attending a pulmonary clinic. *Chest*, 128(4), 2012-2016. <https://doi.org/10.1378/chest.128.4.2012>
- Vanfleteren, L., van 't Hul, A. J., Kulbacka-Ortiz, K., Andersson, A., Ullman, A., & Ingvar, M. (2020). Challenges to the application of integrated, personalized care for patients with COPD. A Vision for the role of clinical information. *Journal of Clinical Medicine*, 9(5), 1-12. <https://doi.org/10.3390/jcm9051311>
- van Walraven, C., Oake, N., Jennings, A., & Forster, A. J. (2010). The association between continuity of care and outcomes: a systematic and critical review. *Journal of Evaluation in Clinical Practice*, 16(5), 947–956. <https://doi.org/10.1111/j.1365-2753.2009.01235.x>
- Watson, L., Schouten, J. P., Löfdahl, C. G., Pride, N. B., Laitinen, L. A., Postma, D. S., & European Respiratory Society Study on Chronic Obstructive Pulmonary Disease (2006). Predictors of COPD symptoms: does the sex of the patient matter? *The European respiratory journal*, 28(2), 311–318. <https://doi.org/10.1183/09031936.06.00055805>

- Wijma, B., Smirthwaite, G. & Swahnberg, K. (red.) (2010). *Genus och kön inom medicin- och vårdutbildningar*. (1. uppl.) Studentlitteratur.
- Williams, S., Sheikh, A., Campbell, H., Fitch, N., Griffiths, C., Heyderman, R. S., Jordan, R. E., Katikireddi, S. V., Tsiligianni, I., Obasi, A., & Global Health Respiratory Network (2020). Respiratory research funding is inadequate, inequitable, and a missed opportunity. *The Lancet. Respiratory Medicine*, 8(8), e67–68. [https://doi.org/10.1016/S2213-2600\(20\)30329-5](https://doi.org/10.1016/S2213-2600(20)30329-5)
- WMA. (2018). World Medical Association declaration of Helsinki Ethical principles for medical research involving human subjects. <http://www.wma.net/en/30publications/10policies/b3/>
- Yildirim, A., Aşilar, R. H., Bakar, N., & Demir, N. (2013). Effect of anxiety and depression on self-care agency and quality of life in hospitalized patients with chronic obstructive pulmonary disease: a questionnaire survey. *International Journal of Nursing Practice*, 19(1), 14–22. <https://doi.org/10.1111/ijn.12031>
- Yohannes, A. M., Kaplan, A., & Hanania, N. A. (2018). Anxiety and depression in chronic obstructive pulmonary disease: Recognition and management. *Cleveland Clinic Journal of Medicine*, 85(2), 11–18. <https://doi.org/10.3949/ccjm.85.s1.03>
- Åberg, J., Hasselgren, M., Montgomery, S., Lisspers, K., Stållberg, B., Janson, C., & Sundh, J. (2019). Sex-related differences in management of Swedish patients with a clinical diagnosis of chronic obstructive pulmonary disease. *International Journal of Chronic Obstructive Pulmonary Disease*, (14), 961–969. <https://doi.org/10.2147/COPD.S193311>
- Öhman, M., Söderberg, S., & Lundman, B. (2003). Hovering between suffering and enduring: the meaning of living with serious chronic illness. *Qualitative Health Research*, 13(4), 528–542. <https://doi.org/10.1177/1049732302250720>