



Exploring symptom clusters in patients with lung cancer

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Abstract

Aim: The aim of this thesis was to explore symptom clusters in patients with lung cancer from a subjective perspective before, during, and after oncological treatment.

Methods: A scoping review was used to map and summarize self-reported symptom clusters, instruments used, and symptom dimensions measured (I). Grounded theory was used to explore the symptom cluster management process during curative oncological treatment from the perspective of patients (II).

Main findings: Patients with lung cancer experience a diversity of symptom cluster constellations that vary in intensity, timing, distress, and quality over time. Several self-reported symptom assessment instruments were identified, most of which measured intensity alone or in combination with timing. Fatigue was the predominant symptom. Other commonly occurring symptoms were dyspnea, pain, depression, cough, and nutritional impact symptoms (I).

Patients' management strategies are shaped by impacting conditions such as knowledge and earlier experience. The patients' pervasive goal and motivation with their management strategies was to survive. Patients often regarded symptoms as unavoidable and normal, which was implicitly perceived as confirmed by health care professionals. Consequently, patients would not always ask for support, and their quality of life was negatively affected (II).

Conclusion: Patients with lung cancer experience multiple severe symptoms occurring in several different symptom clusters, with fatigue as the predominant symptom. Living with symptom clusters is more about survival than actually living. A holistic person-centered and multidimensional symptom assessment is essential to improve and ensure adequate symptom cluster management for patients with lung cancer.

Keywords: Cancer Care, Oncology Nursing, Patients with Lung Cancer, Patient-Reported Outcome Measures, Symptom Assessment, Symptom Clusters, Symptom Management

Sammanfattning

Syfte: Syftet med detta projekt var att utforska symtomkluster hos patienter med lungcancer från ett subjektivt perspektiv före, under och efter onkologisk behandling.

Metod: Via en scoping review sammanfattades själv-rapporterade symtomkluster, använda skattningsinstrument samt symtomdimensioner (I). Grounded Theory användes för att utforska hanteringsprocessen avseende symtomkluster under kurativ onkologisk behandling ur ett patientperspektiv (II).

Resultat: Resultatet visade att patienter med lungcancer upplever en flertal symtomkluster som varierar dels i innehåll och dels i uttryck i symptomdimensionerna över tid. Ett flertal symtomskalor för självskattning identifierades, och de mätte huvudsakligen endast dimensionen intensitet, eller tillsammans med frekvens. Fatigue var det mest förekommande symtomet, och övriga vanligt förekommande symtom i symtomkluster var dyspné, depression, hosta och nutritionsrelaterade symtom (I). Patienternas strategier för symtomhantering formades av påverkansfaktorer såsom kunskap och tidigare erfarenheter. Patienternas övergripande mål och motivation för sina hanteringsstrategier var att överleva. Patienterna betraktade ofta symtomen som oundvikliga och normala, vilket underförstått uppfattades som bekräftat av vårdpersonalen. Därav bad patienterna inte alltid om hjälp, och deras livskvalitet påverkades negativt (II).

Slutsats: Patienter med lungcancer upplever ett flertal besvärande symtom som förekommer i många varianter av symtomkluster, där fatigue är det framträdande symtomet. Att leva med symtomkluster handlar mer om att överleva än att leva. En holistisk personcentrerad och fler-dimensionell bedömning av symtom är viktig för att nå en adekvat hantering av symtomkluster för patienter med lungcancer.

Nyckelord: Cancervård, onkologisk omvårdnad, patienter med lungcancer, patient-rapporterade utfallsmått, symtombedömning, symtomhantering, symtomkluster

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Original papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals (I-II):

- I. Karlsson K, Olsson C, Erlandsson A, Ahlberg K, Larsson M. (2023). Exploring symptom clusters and their measurements in patients with lung cancer: A scoring review for practice and research. *Oncology Nursing Forum*, 50 (6), 783-815. *(Reprinted with permission)*.
- II. Karlsson K, Larsson M, Ahlberg K, Erlandsson A, Olsson C. To get through to survive: Exploring symptom cluster management in patients with lung cancer – A grounded theory study. *(Submitted)*.

Terminology and abbreviations

- **Cancer care** – The health care context, including several specialties and health care professionals, in which a patient with cancer goes through investigations, diagnosis, treatment, and rehabilitation.
- **Oncological care** – The specific part of the health care context within cancer care during which the patient mainly receives oncological treatments, such as radiotherapy, chemotherapy, immunotherapy, and oncological care, including cancer rehabilitation.
- **Oncology nurses** – Nursing professionals working specifically within oncological care, generally with a specialist degree in oncology nursing.
- **Contact nurses within cancer care** – Nurses within the cancer care trajectory specifically assigned as contact nurses to provide support for patients and their families.
- **Health care professionals** – Health care personnel (nurses, doctors, psychologists, counselors, dieticians, physiotherapists, and occupational health assistants) who mainly work in the hospital settings work, often in cancer care teams.
- **Non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC)** – The two major subtypes of primary lung cancer.
- **Patient-reported outcome measures (PROM)** – instruments used to capture a person's perception regarding their own health, including symptoms, daily functioning and quality of life.
- **Health-related quality of life (HRQOL)** – an indicator of impact of health status on quality of life, where multiple self-perceived measurements such as PROMs are combined to assess health issues related to illness and treatment, and usual activities such as self-care, work, recreation and social functioning.
- **Symptom Assessment Scale – Lung Cancer (SAS-LC)** – A two-dimensional symptom assessment scale measuring intensity and distress regarding common lung cancer symptoms.

- **Theory of unpleasant symptoms (TOUS)** – A middle-range theory used to understand, assess, and manage the multidimensional symptom experience and its related components.
- **Grounded theory (GT)** – A method developed as a constant comparative and inductive methodology in qualitative research and used for generating theories that emerge from and are grounded in the empirical data.
- **Constructive grounded theory (CGT)** – Through the constructivist lens, this approach takes the social context into consideration and focuses on interpretation and the active role of the researcher in exploring how individuals make sense of their experiences.

Introduction

The research questions and concepts included in this thesis stem from my professional background as a specialist nurse in oncological care, from meeting many patients with lung cancer in various settings, such as hospital wards, outpatient clinics, palliative care teams, and community health care over the years. I also have a special interest in cancer care development, particularly in areas concerning oncology nursing, and in finding ways to merge clinical and research competencies and knowledge to provide the best possible care for patients with cancer.

Today, the quality of life for patients and their families in the later and last phases of life has increased, as many health care services now involve palliative care teams. However, I found that patients in the earlier parts of the cancer care trajectory within oncological care do not receive the same structured and thorough symptom assessment and management and therefore do not receive adequate supportive care. Hence, these gaps are brought to the fore through the studies in this licentiate thesis.

This thesis is part of a collaborative cancer symptom research project called ‘*SyCL*’ (Symptom Clusters), which involves Karlstad University and Gothenburg University, targeting symptom clusters with the aim of understanding, preventing, and managing symptom clusters during cancer treatment and rehabilitation. The thesis highlights the patients’ perspective; however, the underlying aim is to provide essential knowledge for important stakeholders in cancer care, such as oncology nurses and other health care professionals, researchers, and policy-makers, to inform the direction of further developments.

Patients with lung cancer deal with a number of symptoms due to their illnesses and treatments. These symptoms rarely occur in isolation but rather as symptom clusters in which the grouped and inter-related symptoms generate a synergistic and cumulative effect on health-related outcomes. The symptom cluster experience is viewed as a subjective, multidimensional, complex experience encompassing an intricate interplay between personal characteristics and external

factors. By using a theoretical framework, the research questions and the analysis process are focused on the patients' experiences involving both symptom assessment and symptom management aspects. Thus, this thesis aims to explore the symptom cluster experience in patients with lung cancer from a subjective perspective before, during, and after oncological treatment.

For decades, researchers have identified that patients with lung cancer have a larger symptom burden and suffer more negative effects on their health-related quality of life than patients with other cancer diagnoses. Despite the fact that health care professionals and researchers can provide a larger range of successful treatments and improve survival, representing an excellent advancement in cancer care, patients with lung cancer within the oncological setting do not receive adequate supportive nursing care and symptom management.

By contributing to further outlining the knowledge regarding symptom cluster identification, assessment, and management through mapping and summarizing existing research and exploring patients' experiences, important areas regarding how to enhance person-centered cancer care may be revealed. Such knowledge could further improve oncology nursing practice, foster the development and introduction of effective symptom cluster management interventions, and motivate symptom cluster research to take further actions to make a difference for patients living with lung cancer.

Background

Patients with lung cancer

Being diagnosed with lung cancer encompasses effects on the physical, psychological, social, and existential dimensions of the patients' lives. Patients with lung cancer experience a significant symptom burden and distress (Morrison et al., 2017; Sung et al., 2017), including a compromised quality of life (Liao et al., 2014) and multiple side effects from treatment and symptoms from the disease itself (Bouazza et al., 2017). As lung cancer is socially and culturally frequently associated with smoking, patients with lung cancer are vulnerable to stigmatization, regardless of their smoking status. Lung cancer stigma has been associated with greater levels of depression, anxiety, and symptom severity (Cataldo & Brodsky, 2013) and more negative effects on health-related quality of life (Maguire et al., 2019) for these patients compared with patients with other types of cancer. Lung cancer is also one of the specific diagnoses associated with a higher risk of suicide (Hofmann et al., 2023; Zaorsky et al., 2019).

Patients with inoperable disease generally receive oncological treatment; nevertheless, the median overall survival rate is poor, and mortality is still high among patients with lung cancer (Hansen et al., 2020). On a positive note, due to recent advancements in treatments, even patients with advanced-stage lung cancer can now live for an unexpectedly long time. However, the uncertainty and struggle regarding life priorities and meaning-making remain, emphasizing the importance of understanding patients' experiences and their need to be understood in their situations (Al Achkar et al., 2020). Long-term survivors have been identified as having unmet rehabilitation needs, as they continue to experience significant physical, psychological, and functional concerns after treatment (Petrillo et al., 2021). Among patients with lung cancer, a wide spectrum of supportive care needs have been illustrated, ranging from general to more complex needs that affect their lives in various aspects (Maguire et al., 2013; Cochrane et al., 2022). Hence, holistic support is required during the cancer care trajectory to improve symptom cluster management and alleviate the effects on outcomes concerning all dimensions of patients' lives.

Lung cancer

Lung cancer is one of the most common cancers and remains the leading cause of cancer-related deaths in Europe as well as worldwide. Around two thirds of all lung cancer deaths are attributable to smoking, and 5–20% to air pollution (Bray et al., 2018; Kocarnik et al., 2022; Malvezzi et al., 2023). Primary lung cancer is a wide diagnosis that includes two major histologically and molecularly heterogeneous subtypes: non-small cell lung cancer (NSCLC) and small-cell lung cancer (SCLC) (Travis et al., 2015). NSCLC accounts for approximately 80–85%, SCLC 10–15%, and carcinoid type tumors 5% of all lung cancers (Vrtis, 2022). Prognosis depends on clinical and tumor-related factors, such as the patients' performance status and the tumor stage, as well as sex, age, and tumor biology, including immunological factors (Weinberg et al. 2021). The lung cancer incidence in Sweden for the period 2017–2021 indicates that 4337 persons were diagnosed per year, and the number of persons living with lung cancer at the end of 2021 was 14,389 in total. Relative survival rates for males/females during 2017–2021 were 54.0/61.7% for 1 year and 25.1/33.0% for 5 years, respectively (Larønningen et al., 2023). As patients with advanced stages of lung cancer can often live for years rather than months, the lung cancer experience is now more often similar to that of a chronic disease (Al Ackar et al., 2020).

The lung cancer trajectory

Symptoms indicate a change in normal functions and a threat to health as subjectively perceived by patients (Lenz et al., 1997) and are generally the reason for seeking medical help. Common symptoms experienced when being diagnosed with lung cancer are persistent cough, hemoptysis, chest and/or metastatic pain, breathlessness, weight loss, fatigue, and fever; but not rarely, the patient may be asymptomatic (Xing et al., 2019). Over time, it has been identified that hemoptysis is becoming less common, while cough and dyspnea have increased as index symptoms, which is important for symptom awareness and early diagnosis initiatives (Chowienczyk et al., 2020). Compared with having cough alone as an index symptom, patients presenting with more symptoms at diagnosis have shorter survival times (Athey et al., 2018). Generally, the more advanced the stage at diagnosis, the more likely that the patient will experience symptoms as well as physical signs

(Xing et al., 2019). Although there are sex-specific differences indicated in survival rates (Larønningen et al., 2023), there are no differences in frequency or number of symptoms or effect of smoking status when comparing men and women at the time of diagnosis (Ruano-Ravina et al., 2021).

Regarding the standardized cancer patient pathways that start when a patient presents with specific alarming symptoms, the lead time target from a suspected lung cancer diagnosis until the start of treatment is 30-44 days, depending on treatment modality, but only 30% of diagnosed patients meet the target time for commencing treatment (Borg et al., 2023). Conceivably, patients with lung cancer spend weeks, and sometimes months, living with symptoms and awaiting proper investigations and results needed for commencing treatment, which affect their symptom management.

After receiving the diagnosis, treatment options for patients with lung cancer are influenced by factors including stage of cancer at diagnosis, histological findings, performance status and the patients' preferences. Surgery, chemotherapy and/or radiotherapy are standard treatment options for many, and other systemic treatment modalities, such as targeted therapies and immunotherapy, have been on the rise since 2015 (Howlader et al., 2020). For patients with NSCLC, major improvements have been made regarding the identification of new targets and mechanisms of resistance to current therapy, and the development of new agents, such as targeted therapies and immunotherapy. Although non-curative, these therapies have improved patients' survival times. For patients with SCLC, there have been limited improvements (Borneman & Koczywas, 2023; Vrtis, 2022).

As every treatment brings a unique set of toxicities and effects, both short- and long-term, nursing care needs to be diligent and persistent in the assessment and management of symptoms and their effects on quality of life (Borneman & Koczywas, 2023). For patients to actively participate in decision-making and understand the treatment, it is crucial to establish realistic expectations of the treatment's effects and its impact on quality of life (Lee et al., 2023). The patient's right to have an impact in decisions concerning their care is a core value of person-

centered care (McCormack & McCance, 2016), but patients also tend to underestimate the possibility of experiencing severe side effects (Lee et al., 2023). The respect and understanding of the patient's situation need to be emphasized, along with the experience and responsibilities of health care professionals, when targeting the symptom cluster experience and management, that is, dealing with multiple co-occurring symptoms that affect their functions and quality of life.

The cancer care trajectory is a long-term partnership between the patient and the health care professionals, as support is required not only during active treatment but in all aspects of cancer care. Through the cancer care trajectory, contact nurses are assigned to inform and support the patients, and to continually assess, assist in management and follow-up their symptoms and needs related to their illness and treatment in a structured and evidence-based way. In Sweden, the role of the contact nurse in cancer care was established in the Swedish National Cancer Strategy (SOU, 2009:11) to provide high-quality care and support and is commonly available for patients and their significant others during the cancer care trajectory.

The symptom cluster experience

Symptom clusters

Symptoms rarely occur in isolation, and multiple co-occurring symptoms are common among patients with cancer. Symptoms occurring in clusters have a synergistic and cumulative effect on health-related outcomes compared with single symptoms, thus having important implications for clinical practice and research (Kwekkeboom et al., 2022; Miaskowski et al., 2017). This thesis relies on the symptom cluster definition by Kim et al. (2005) as established groups of two or more symptoms related to each other and relatively independent of other clusters, thereby illuminating specific underlying concepts of symptoms that may or may not share the same etiology.

When exploring patients' perceptions of their symptom clusters, the temporal order and direction of symptom relationships in clusters would vary, although researchers have established that patients' priority clusters usually include two symptoms of constant duration and one

intermittent symptom (Kwekkeboom et al., 2022). In general, the number and specific symptom constellations within a cluster and the symptom dimensions being measured have been found to be highly variable (Ward Sullivan et al., 2018). Symptom clusters are either clinically defined by assuming the relationships among symptoms or are statistically defined by exploring statistical relationships between symptoms. The methods used to investigate symptom clusters in research are the ‘most-common symptom’ approach (a priori) and the ‘all-possible symptom’ approach (de novo). The a priori approach explores pre-defined symptom clusters generally consisting of two to three symptoms, which are then investigated based on a presumed relationship. The de novo approach explores correlations between many symptoms, and several clusters consisting of a varied number of symptoms may be identified, often containing more than four symptoms per cluster (Xiao, 2010). There is a lack of consistency in the symptom cluster research literature regarding methodological approaches and statistical strategies, such as how they are measured and how data are collected (Miaskowski et al., 2017). Therefore, there is a need for a comprehensive mapping of symptom cluster research to obtain an overview of the available evidence and identify areas for further research.

Symptom clusters among patients with lung cancer

Generally, previous symptom cluster research in the oncological setting has included patients with heterogeneous cancer diagnoses, and a limited number of studies have focused exclusively on patients with lung cancer (Xiao, 2010; Ward Sullivan et al., 2018). Symptom cluster research exploring symptom clusters in patients with lung cancer has used both a priori and de novo methods, and investigated clusters such as fatigue, dyspnea, and cough (Cheville et al., 2011a, 2011b); fatigue, shortness of breath, cough, pain, and anorexia (Brown et al., 2011); breathlessness, fatigue, and anxiety (Chan et al., 2005); breathlessness, cough, and fatigue (Yorke et al., 2015); fatigue, weakness, nausea, vomiting, loss of appetite, weight loss, and altered taste (Gift et al., 2003); and pain, fatigue, and insomnia (Hoffman et al., 2007). Hensch et al. (2009) found that fatigue and appetite appeared in pain and respiratory clusters and that fatigue correlated highly with symptoms in all their defined clusters. Russell et al. (2019) and Li et al. (2021) identified

six symptom clusters over time in patients with lung cancer receiving chemotherapy, and three of these clusters were relatively stable over time. Zhang et al. (2022) identified five symptom clusters among patients treated with immunotherapy, although their symptom burden was mainly at a low level, and performance status, a history of chemotherapy, and financial factors affected certain clusters.

Symptom cluster assessment and management

Within oncological care, continuous symptom assessment and management is critical in delivering high-quality person-centered care. As symptoms are the subjective experience of patients, they initiate the assessment, as they notice something different, interpret what it may be, and decide on how to act to manage the situation.

The experience of symptoms may vary by culture, as it encompasses a learned component of interpreting and expressing symptoms. The patient's assessment is influenced by their personal characteristics, such as emotional state, coping skills, level of knowledge, situational factors in their environment, such as access to resources and health care, and socioeconomic factors (Lenz & Pugh, 2018). Other factors affecting patients' awareness and communication may also include lung cancer stigma (Cataldo & Brodsky, 2013; Sung et al., 2017), previous cancer experiences, and health literacy (Sørensen et al., 2012).

As most patients with lung cancer experience several symptoms simultaneously and have a high symptom burden (Lehto, 2016), symptom assessment and management are essential during the cancer care trajectory. Within cancer care, symptom assessment and measurement should be carried out systematically via the use of patient-reported outcome measures (PROM) during treatment and follow-up to improve the quality of care and target disease-specific issues or symptoms (Cavanna et al., 2020; Graupner et al., 2021). If symptoms are measured through a self-reported questionnaire, it might aid health care professionals in identifying and supporting patients with symptom management in a more timely manner (Dai et al., 2022; Maguire et al., 2013). A general assessment of overall health-related quality of life, supplemented with disease-specific instruments, has been recognized as the most effective method (Cavanna et al., 2020).

Further, symptom management research has highlighted a change from targeting single symptoms to focusing on symptom clusters to more efficiently improve symptom management (Fei et al., 2023). Symptom cluster research is considered to have clinical importance (Aktas et al., 2014) and to facilitate effective symptom management (Rha & Lee, 2019).

Symptom cluster management is a dynamic process and should integrate the patients' own resources regarding self-care and self-efficacy, along with nursing care and interventions, to improve health-related outcomes (Brant et al., 2010). As patients live longer with advanced cancer and receive new treatments, they have to face challenges concerning side effects, uncertainty regarding their future and prognosis, and cancer rehabilitation issues, such as maintaining a healthy lifestyle and dealing with long-term symptoms. Therefore, support should be provided in a patient-centered manner to ensure that patients' needs are met and outcomes are improved (Temel et al., 2022).

Theoretical frameworks

To clarify the conceptual structures of how symptoms, function, quality of life, and related variables influence health and well-being in patients with lung cancer, the revised Wilson and Cleary model of health-related quality of life (Ferrans et al., 2005) provides support for the understanding of the symptom cluster experience, symptom cluster management are related to its outcomes and prerequisites. The original version of the model (Wilson et al., 1995) linked components from biomedicine and social sciences, and the revised version by Ferrans et al. (2005) further shaped the health-related quality of life (HRQOL) model for application within health care and nursing (Figure 1). The model hypothesizes that the characteristics of the individual and the environment are associated with the other components.

Biological function includes variables related to bodily functions, such as the type of lung cancer, comorbidities, and biomarkers. *Symptoms*, the second component, relate to patients' subjective experiences of an abnormal state, such as fatigue, breathlessness, and loss of appetite. *Functional status* is defined as the ability to perform physical, social,

role, or psychological functions. The biological function and symptoms affect the functional status of the patient, as, for example, a lung tumor may cause inflammation, pain, and difficulty breathing; therefore, the patient is unable to function at normal capacity in daily life. The fourth component, *general health perceptions*, is described as the patients' subjective measure synthesizing an overall health evaluation, which is influenced by the other components. Lastly, *overall quality of life* encompasses the patient's well-being in relation to their satisfaction with life as a whole (Ferrans et al., 2005).

This thesis will focus on the patients' experiences of *symptoms*, but as the revised Wilson and Cleary model illustrates, other components are associated with the symptoms. Thus, symptom management is considered essential for maintaining functional status and HRQOL. The characteristics of the individual and the environment are also important components concerning the symptom cluster experience and management, as they affect the patients' thoughts, feelings, and actions.

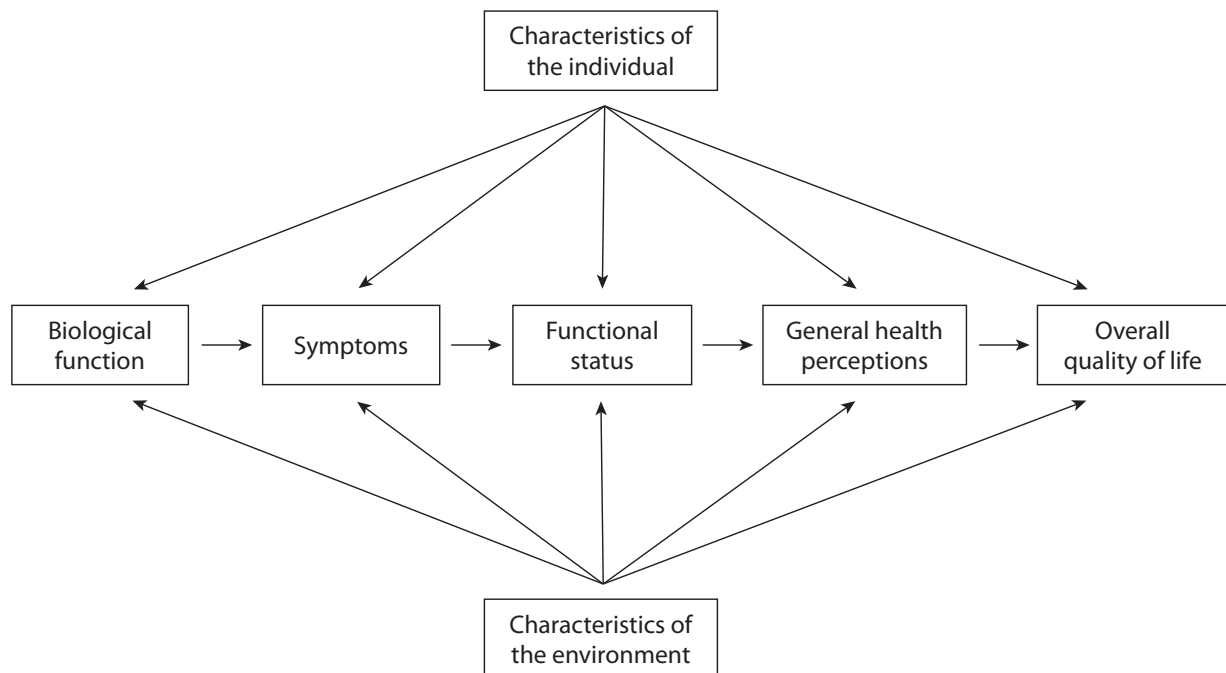


Figure 1. Revised Wilson and Cleary model for health-related quality of life (Ferrans, Johnson-Zerwic, Wilbur, & Larson, 2005). Used with permission.

The middle-range theory of unpleasant symptoms (TOUS) is used as the primary framework in this thesis. TOUS was originally presented

by Lenz, et al. (1995) and was updated in 1997 (Lenz et al., 1997). Compared to the first version, the latter asserts that while symptoms may be separated from one another, they usually exist in co-occurrence with other symptoms. TOUS thereby illustrates the symptom cluster experience, as well as its related influencing factors and the result of the symptom experience (Lenz et al., 1997), with quality of life potentially recognized as an outcome or the consequences of the symptom experience (Lenz & Pugh, 2018). TOUS (Figure 2) contains three main reciprocal components: the *multidimensional symptom experience*, *factors* influencing the symptom experience, and *performance* (i.e., the consequences of the symptom experience). The symptom experience is comprised of four symptom dimensions: intensity, timing, distress, and quality. Factors influencing the symptom experience are described as physiological, psychological, and situational antecedents which can be interactive. There may be moderating effects between the influencing factors and symptoms, as well as a reciprocal, direct impact from symptoms back onto the influencing factors (Lenz et al., 1997).

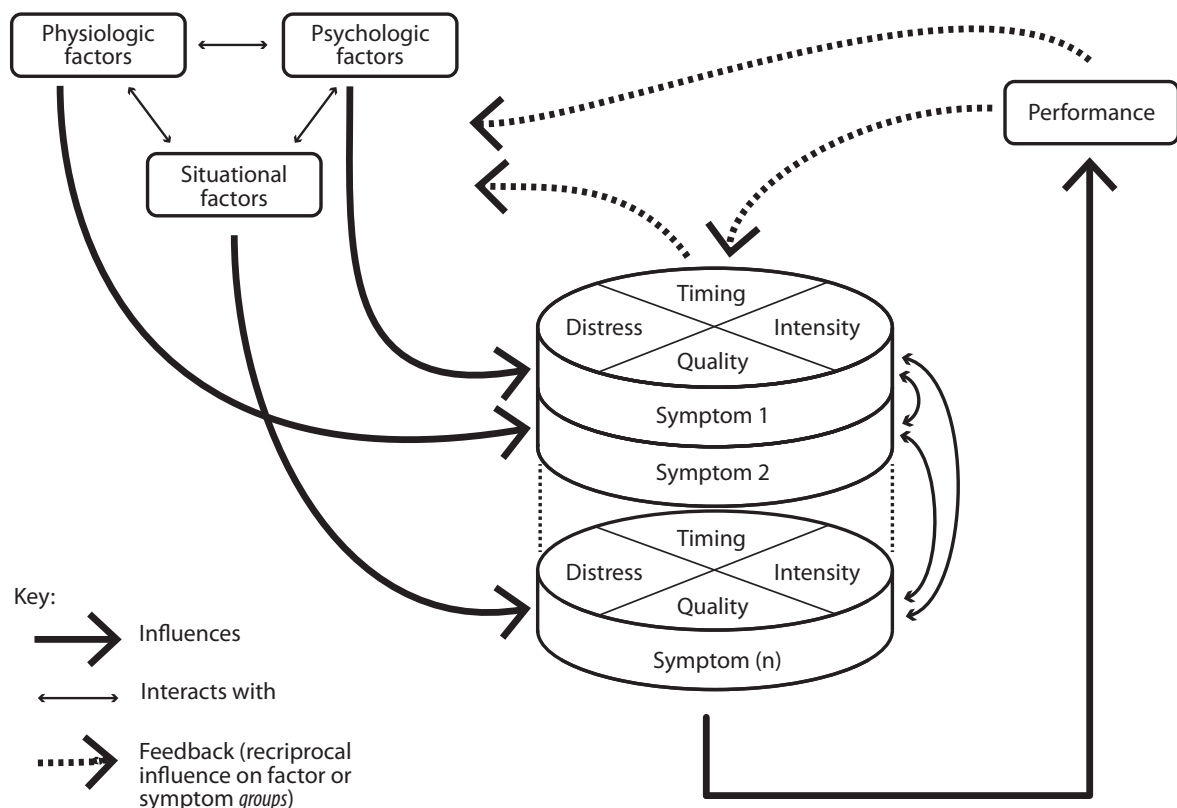


Figure 2. The theory of unpleasant symptoms (Lenz et al., 1997). Copyright by Wolters Kluwer Health, Inc. Reprinted with permission.

TOUS has been used in symptom cluster research within the oncology setting (Chan et al., 2005; Fox & Lyon, 2007; Gift et al., 2004; Hoffman et al., 2007; Kim et al., 2015; Wu & Harden, 2015; Xiao et al., 2021) and applied frequently in methodological design and analysis in different populations in symptom research (Blakeman, 2019).

Several other models that theorize the symptom experience and management exist in the literature (e.g. Armstrong, 2003; Dodd, 2001; Haworth & Dluhy, 2001). Although TOUS does not include symptom management as a concept, it was considered a comprehensive and holistic framework for exploring the symptom cluster experience in this thesis. TOUS is considered a useful model for the development of management strategies and interventions to decrease symptom burden (Blakeman, 2019) and for examining symptom clusters and their influencing factors and outcomes (Lee et al., 2017).

Rationale

This thesis aims to contribute to the knowledge and understanding of symptom cluster experience and management from the perspective of patients diagnosed with lung cancer, with the overall goal of identifying areas such as how to optimize symptom cluster management within the oncological context.

The cancer care trajectory is a long and complex road, and besides the lung cancer experience in itself, patients are supposed to handle numerous symptom clusters during their illness and treatment. According to previous research, patients with lung cancer are an exposed group with many symptom concerns and needs regarding supportive care during the cancer care trajectory. Although symptom cluster research has been undertaken for more than 20 years in the oncological setting, it is methodically fragmented regarding the lung cancer population and is difficult to condense.

Therefore, there is a need to map the symptom cluster experience to set the scene for future measures regarding oncology nursing and further research. Further, little is known about the patients' personal experiences and conditions in the process of symptom management during oncological treatment. Researchers and health care professionals can benefit from knowledge gained from the patients' perspective to understand, prevent, and alleviate symptom clusters in cancer care.

Overall and specific aims

The overall aim of this thesis was to explore symptom clusters in patients with lung cancer from a subjective perspective before, during, and after oncological treatment.

The specific aims were:

- I. To explore symptom clusters in patients with lung cancer and to describe how the included symptoms and symptom dimensions are measured.
- II. To explore the symptom cluster management process from the perspective of patients with lung cancer within the oncological care context.

Methods

This thesis consists of two studies (I and II), which will be referred to by their Roman numerals. The included studies and their designs are displayed in Table 1. The research design of this thesis was descriptive and explorative, using a scoping review of the literature and a qualitative interview study to address the overall aim of the thesis.

Table 1. Overview of the studies included in the licentiate thesis

Study	Design and method	Data collection	Sample	Analysis
I	Literature overview via a scoping review	Data base searches	53 articles from 48 studies representing 11,948 patients	Mapping and summarizing according to Arksey and O'Malley (2005) and Levac <i>et al.</i> (2010)
II	Explorative with a qualitative approach	Individual interviews and a two-dimensional symptom assessment instrument	15 patients receiving curative oncological treatment	Constructive grounded theory according to Charmaz (2014)

Methodological and theoretical stances

Through the studies' specific aims, an understanding and description of the research area is sought to illuminate and answer the overall aim of the thesis. The methods were chosen according to the aim of the individual study, and the epistemological and ontological viewpoints of this research were reflected in the selected methods and the theoretical frameworks used for structure.

The ontological claims in philosophies regarding the nursing discipline state what is believed about the nature of human beings, health, the environment, and nursing. Epistemic claims in nursing address how knowledge related to these concepts is developed (Fawcett & DeSanto-Madaya, 2013). Although no philosophical statements regarding TOUS have been clearly specified by the originators, TOUS can be assumed to reflect the reciprocal interactional worldview (Lee et al., 2017). The reciprocal interaction worldview assumes a person to be holistic while acknowledging parts but only those with meaning within the context of the whole human being. Human beings and the environment are regarded as having reciprocal interactions, with changes in behavior occurring due to multiple individual and environmental factors. Empirical observations and the use of both quantitative and qualitative methods of inquiry are emphasized in knowledge development (Fawcett & DeSanto-Madaya, 2013).

The scoping review study (I) was conducted to map and summarize the existing evidence base. While the review provided broad insight into the research topic from quantitative and qualitative studies, the methodological approach in the interview study (II) added depth and richness. According to the constructivist grounded theory used in study II, reality is considered multiple, processual, and constructed (Charmaz, 2014). The constructivist GT approach assumes a relativist epistemology, acknowledging the multiple standpoints of both research participants and the researcher by viewing knowledge as socially produced through our interactions. The pragmatic constructivist approach in GT considers knowledge to be co-constructed in the interaction between the researcher and the study participants (Charmaz, 2014). Relativist ontology holds that the belief in reality is the human experience, and human experience is reality. Therefore, the purpose of

science is to understand the subjective experiences of reality and multiple truths (Levers, 2013).

Scoping review study (Study I)

Design

For study I, a scoping review methodology was chosen because the intention was to map and summarize the existing evidence regarding the contents and measurements of symptom clusters and to identify knowledge gaps that still needed to be addressed. The scoping review is applicable in nursing research and presents the state of the evidence, may contribute to theory development, and is of relevance for practice and policymakers (Arksey & O'Malley, 2005). The methodology followed the five stages proposed by Arksey and O'Malley (2005), the updates regarding the PRISMA-ScR (Peters et al., 2020), and the clarification of each stage (Levac et al., 2010). The stages presented below include (1) identifying the research question, (2) finding relevant studies, (3) selecting studies, (4) charting the data, and (5) collating, summarizing, and reporting the results. The optional sixth stage—to consult with a reference group—was not used.

Identifying the research question

To further specify the specific area of interest, the research questions for study I were as follows:

- Which symptom clusters exist in lung cancer research?
- How do the de novo and a priori clusters differ in symptom constellation?
- Which instruments are used in symptom cluster research (i.e., how are the symptoms measured)?
- How are the symptom dimensions made evident in quantitative and qualitative research?

Data collection

Finding relevant studies and selecting studies

For the next stages in the review process, relevant studies were searched and selected by establishing inclusion and exclusion criteria, determining key search terms and performing database searches. The inclusion criteria were studies conducted on adult patients with lung cancer, at or after the time of diagnosis, and either before, during, or after oncological treatment. There needed to be self-reported experiences of multiple co-occurring symptoms/symptom clusters (i.e., a minimum of two related concurrent symptoms).

Peer-reviewed articles in English using quantitative, qualitative, or mixed methods were included. The exclusion criteria were studies conducted on patients with lung cancer with surgical treatment only, and patients in the late end-of-life/dying phase. Studies describing symptom clusters before lung cancer diagnosis and studies with self-reported multiple symptom data but no evidence of clustering were also excluded, as were other reviews and gray literature. Systematic and structured literature searches were performed in PubMed, CINAHL, Scopus, and the Cochrane Library, with guidance from an experienced librarian. Specific headings, MeSH terms, and keywords were used in combination with free-text search terms by using Boolean operators to obtain both breadth and depth. The search terms (Table 2) and eligibility criteria guiding the study selection were discussed among the authors until a consensus was reached.

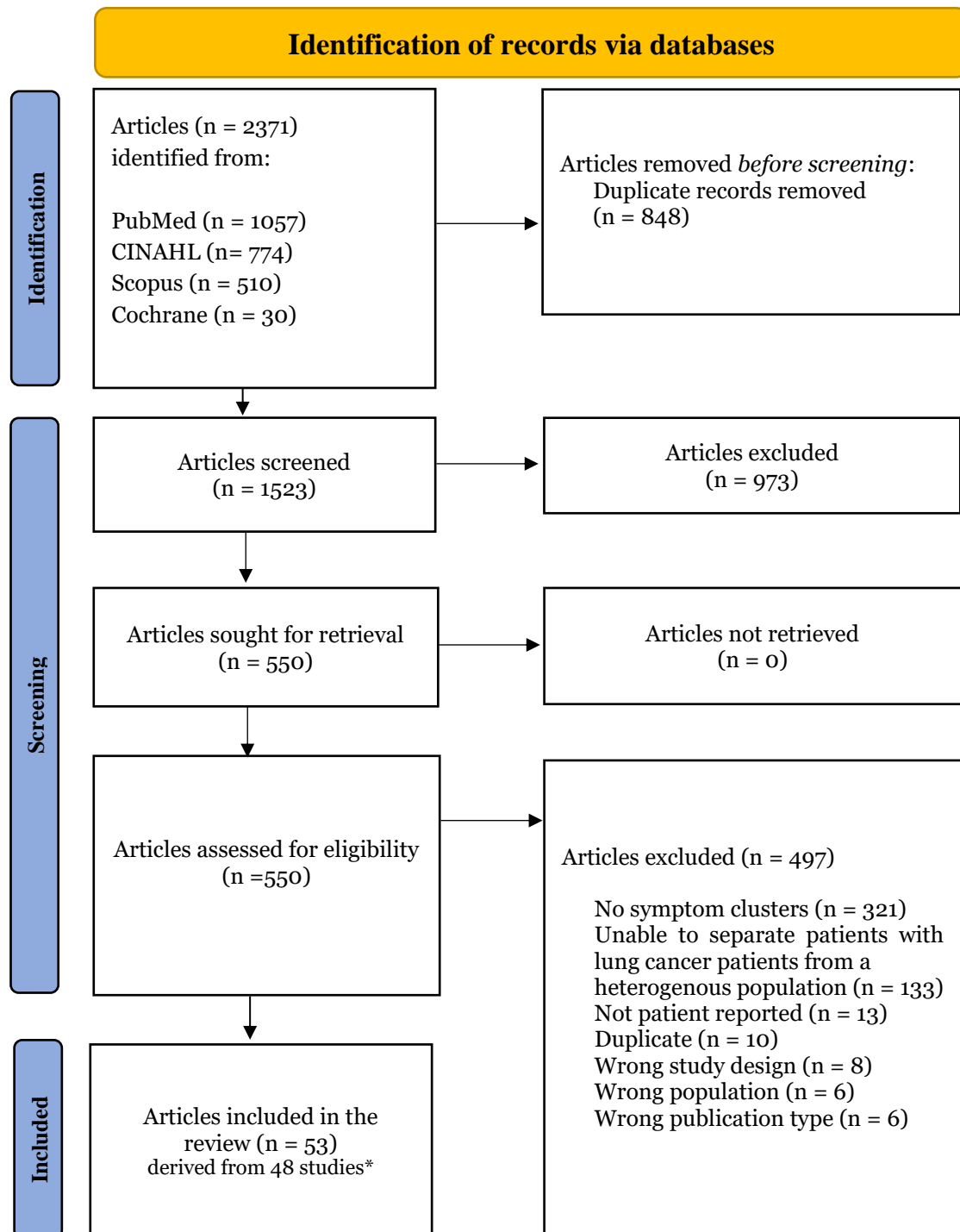
Table 2. Key search terms in the search strategy

Key search terms
lung cancer OR lung neoplasm
AND
patient experiences OR patient descriptions OR patient reported outcomes
AND
symptoms OR symptom cluster OR multiple symptoms OR symptom distress OR symptom burden OR symptom dimensions OR symptom intensity OR symptom quality OR symptom severity OR symptom frequency OR meaning

Searches were conducted with no limitations to the earliest year of publication, as the concept of symptom clusters has been described since the early 2000s, but the co-occurrence of multiple symptoms has been researched earlier. The searches ended at 31 december 2021. Selected articles (n = 2371) were further sorted, and duplicates were removed through the use of EndnoteX8/X9 and Rayyan QCRI software (Ouzzani et al., 2016).

The eligibility criteria were used to screen title/abstract of the remaining articles. The screening process was blinded and conducted by a minimum of two authors for each article, with the first author screening all 1523 articles and the other four authors screening one-quarter of the articles each. Any discrepancies were discussed within the group until consensus was reached.

The selection process is presented in a PRISMA diagram (Figure 3) (Page et al., 2021). Following full-text screening (n = 550), 53 articles from 48 studies met the eligibility criteria. The included records were referred to as articles instead of studies, since a study may occasionally yield more than one article.



* Five pairs of articles involved the same participants, therefore the total number of studies was 48.

Figure 3. PRISMA flow diagram of the selection process. Source: modified from the flow diagram presented by Page et al. (2021).

Sample characteristics

The final sample included 53 articles from 48 studies conducted in 15 countries. The years of publication spanned 1993 to 2021. Six articles had a qualitative design, forty-six had a quantitative design, and one used a mixed method. The population consisted of 11,948 patients with lung cancer who were at various stages in terms of their cancer care trajectory—that is, newly diagnosed, currently receiving treatment, or finished treatment.

Quality assessment

The quality of the included articles was assessed (Daudt et al., 2013) using the Mixed Method Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT includes an appraisal of five methodological criteria domains that vary depending on the study design. Each domain assessment is scored, and the total score (0–100) is presented in the results. A higher score indicates higher quality. In total, 46 articles scored a moderate-high quality score (80–100), and 7 scored lower (40–60). The main area that produced a low score was the criteria regarding risk of nonbiased sample, as the information was lacking or indicated a high nonresponse bias. The quality appraisal was performed by the first author and then discussed and verified by another author.

Data analysis

Charting the data, and collating, summarizing, and reporting the results

These last stages of the review process included analyzing and presenting the data. A data extraction template was developed by the authors according to the aim and research questions to organize the data extraction. The findings were summarized in a table with relevant information, such as the type of study, participants, country, and main findings. Furthermore, the initial analysis divided the articles by their methodology, as some investigated a priori symptom clusters and others investigated de novo symptom clusters. All identified symptom clusters were charted per article. The most prevalent symptoms among the symptom clusters were identified. A comparison was also made concerning other symptoms that were likely to cluster with these

prevalent symptoms, depending on the methodology. For further comparisons, the related individual symptom items were combined and sorted into symptom categories. The symptom assessment instruments used were charted in a separate table, together with information regarding the symptom dimensions used. The symptom dimension-related data were identified using the theoretical framework (Lenz et al., 1997) for guidance regarding the interpretation of each dimension.

Qualitative interview study (Study II)

Design

For study II, a qualitative design with a constructivist grounded theory approach according to Charmaz (2014) was used to explore how patients' experienced the symptom cluster management process.

Grounded theory

Grounded theory (GT) as a method was originally developed by sociologists Glaser and Strauss (Glaser, 2016). Research regarding chronic illness stems from the Chicago School of including field research and symbolic interactionist social psychology. GT has been used to address specific empirical problems involving individual experience as the primary focus of analysis. GT research has emphasized how people with chronic illness manage their lives and its effects on self and identity. These studies include narratives concerning quality of life, suffering, and loss of autonomy and what it means from the patients' experience of living with illness (Charmaz, 2010). The reflexive stance in constructivist GT toward peoples' situations, actions, understanding, and knowledge is made evident through social construction (Charmaz, 2014).

Participants

The inclusion criteria were as follows: The participants were adult patients with lung cancer receiving radiotherapy with curative intent and with adjuvant or concurrent chemotherapy. The participants needed to have two or more symptoms in relation to their illness and/or treatment to be included, as well as be able to understand and sign informed consent in Swedish and participate in an individual interview. The sample consisted of 15 patients (8 males and 7 females),

aged 51–77 (mean 66 years). The participants were outpatients at a regional hospital in Sweden; some stayed at home, commuting daily to their radiotherapy appointments, whereas others stayed at a patient hotel at the hospital site. Two of the participants had received chemotherapy prior to radiotherapy, and 13 had received chemotherapy concurrently with radiotherapy.

Data collection

The participants were recruited by nurses in the radiotherapy department at their initial consultation or during their first week of treatment. The nurses provided the participants with verbal and written information regarding the study, and signed consent forms were collected from those who accepted participation. Another six patients initially accepted the invitation but did not participate due to unexpected medical complications, alteration from curative to palliative treatment intention, or a change of mind. Initially, strategic sampling was employed, but during the analysis, theoretical sampling was also conducted to collect additional data based on the preliminary categories. Individual face-to-face in-depth interviews took place with two participants in 2017 by the last author, and from November 2019 – September 2021, by the first author (n = 13) of this study. The interviews lasted on average 60 minutes (range 49–77 minutes). The interviews were digitally recorded, and the interviewer wrote memos after each interview, including initial reflections, non-verbal communication, and non-recorded communication.

By starting with an open-ended question such as, ‘Can you tell me how lung cancer has affected your life?’ the patients were encouraged to talk freely about their experiences. Further, thematically focused questions regarding symptom clusters and symptom cluster management, such as ‘How does it (symptom or symptom cluster) make you feel?’, ‘What makes it (symptom or symptom cluster) better, or worse?’, ‘What would you do to prevent and/or alleviate it (symptom/symptom cluster)?’, and ‘Who would you turn to for support?’, were asked to ensure valid data related to the research questions were gathered. The interview guide was slightly modified during the data collection and data analysis process to enable the expansion and definition of the theoretical categories (Charmaz, 2014). Data were also collected via a

two-dimensional symptom assessment scale (Appendix 1), developed for patients receiving radiotherapy and was psychometrically evaluated by Langegård et al. (2021). Inspired by the design of the Quality from the Patient's Perspective instrument (Wilde et al., 1994) and based on TOUS, the scale measures a core set of 13 common cancer symptoms regarding intensity (1 = not at all, to 4 = very much) and distress (1 = of no concern, to 4 = of greatest concern). For this study, four additional lung cancer-specific items were added relating to respiratory symptoms, inspired by the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Lung Cancer 13 module (EORTC LC-13) (Bergman et al., 1994). The patients could also add optional symptoms they experienced.

Data analysis

In study II, data analysis was conducted according to Charmaz's (2014) grounded theory method approach. Data collection and preliminary analysis were conducted concurrently. Transcripts from the interviews and answers from the symptom assessment scale were used as data. Reflective memos written after each interview and theoretical memos written during the analysis were used in the process. Initial coding of the interviews ('line by line') was performed by the first author, during which the initial codes were kept closely related to the participants' original accounts of actions to avoid any assumptions in the early stages. This was followed by focused coding, which involves creating mind maps, sorting, and comparing codes as a whole rather than the individual narratives. The focused codes were verified and developed by a constant comparison to the data and discussed among the group. Lastly, abductive theoretical coding related to the theoretical framework of TOUS, and more theoretically focused memos aimed to increase abstraction and identify significant relationships between the categories. Theoretical saturation was considered attained when no new properties emerged from the theoretical categories. The Statistical Package for Social Sciences (SPSS), version 29.0.1.0 was used for analyzing descriptive statistics (frequencies and means) regarding the data collected from the symptom assessment scale.

Ethical approval and considerations

This project was carried out in accordance with good research practices based on the fundamental ethical principles of the Declaration of Helsinki (World Medical Association, 2013).

Study I – In a scoping review, publicly available previously published research is used as data, no sensitive or confidential data are collected from the participants themselves, and there is no requirement for approval by a research ethics committee. Nonetheless, ethical considerations according to fundamental principles are warranted. Reliability and honesty are reflected in the methodological rigor and quality in reviews, and reviewers should consider the quality and relevance of the evidence reported in the primary research with respect to the perspectives of the authors and research participants of original studies and the purpose of the review (Suri, 2020). All included studies in this study needed to be published in a peer-reviewed journal, as peer-reviewers help validate research and raise the quality of articles. The transparency and rigor of reporting the review process were supported by the use of the PRISMA statement (Moher et al., 2009; Tricco et al., 2018). A quality appraisal was performed and reported on the included articles in the final sample (Daut et al., 2013).

Study II – Participants were provided with both verbal and written information describing the purpose and procedure of the study. Written informed consent, stating that participation was voluntary and could be ended at any time, was obtained from all participants (World Medical Association, 2013). This study received approval from the Ethical Review Board in Uppsala (Dnr. 2017/112), and consent to conduct the study was obtained from the head of the oncology department at the participating hospital. The results are presented on a group level, so that no specific individual can be linked to any specific information. However, care was also taken when analyzing and presenting the data that all participants' voices were present. The risk of strain or personal harm to the participants was considered low. The potential to gain knowledge from the patients' perspectives was considered beneficial and justified in this field of research. If the interview provoked negative emotions, the participants could consult with counselors in

the oncology department or contact the research group. The results should benefit patients with lung cancer as a group, with this knowledge guiding practice and interventions in the future, and could also benefit the individual participant, as it may convey a sense of importance of their experiences, being listened to, and an opportunity to contribute to better cancer. All collected data have been handled according to the General Data Protection Regulation (European Parliament and the Council of the European Union (EU) 2018/1725). The primary data were stored on a secure cloud server at the university and protected from unauthorized access. Documents containing personal information have been coded to ensure confidentiality and are stored in a locked safe. The data remain archived at the university and will be deleted after 10 years according to European and Swedish legislations.

Main results

The main findings from the scoping review (I) include descriptions and variations in symptom cluster constellations depending on methodology, and a summary of the patient-reported outcome instruments used, together with the measured or described symptom dimensions. The findings from the grounded theory study (II) are portrayed in a situational theoretical model that summarizes how patients with lung cancer experience and manage symptom clusters and identifies the impacting conditions of the management process.

Study I

Descriptions and variations of symptom cluster constellations

The scoping review identified a large variety of symptom clusters reported among patients with lung cancer in 53 articles. The number of symptom clusters varied from one to 49 different constellations per article. The symptoms occurring in clusters would vary depending on whether the clusters were defined in advance (a priori) or not (de novo). The de novo approach is more common than the a priori approach in research to date. In articles (n = 13) with an a priori approach, 15 clusters were identified, and among articles (n = 40) with a de novo approach, 270 clusters were found.

Out of the 40 articles with a de novo approach, 15 indicated their aim of investigating symptom clusters de novo (hereby described as “with cluster aim”). The other 25 articles did not specify this as an intentional aim (hereby described as “without cluster aim”); nonetheless, their analysis and results presented co-occurring symptoms, that is, symptom clusters according to the reviews’ definition.

The six most prevalent symptoms in the cluster constellations were identified: fatigue, dyspnea, pain, cough, depression, and appetite loss. Comparisons were made, and depending on the methodological approach, there were differences in symptom cluster constellations identified, as shown in Table 3. In this table, the percentages refer to the extent of the presence of fatigue, dyspnea, pain, cough, and appetite loss among the particular types of articles and the symptoms with which they most frequently cluster.

Table 3. Symptoms frequently occurring in clusters and their clustering symptom categories

In a priori articles (n= 13)	Clusters with symptom categories	In de novo articles without cluster aim (n = 25)	Clusters with symptom categories	In de novo articles with cluster aim (n = 15)	Clusters with symptom categories
Fatigue (100 %)	Psychological symptoms (69%) Respiratory symptoms (all) (54%) Pain symptoms (54%)	Fatigue (76 %)	Psychological symptoms (63%) Respiratory symptoms (all) (53%) Nutritional impact symptoms (42%)	Fatigue (100 %)	Nutritional impact symptoms (67%) Psychological symptoms (60%) Pain symptoms (33%)
Dyspnea (62%)	Fatigue (75%) Psychological symptoms (50%) Respiratory symptoms (others) (38%)	Dyspnea (72 %)	Psychological symptoms (56%) Fatigue (44%) Respiratory symptoms (others) (39%)	Pain (87 %)	Nutritional impact symptoms (69%) Psychological symptoms (62%) Fatigue (46%)
Pain (54%)	Fatigue (86%) Psychological symptoms (57%) Nutritional impact symptoms (29%)	Pain (60 %)	Psychological symptoms (60%) Fatigue (47%) Nutritional impact symptoms (40%)	Depression (80%)	Psychological symptoms (others) (83%) Fatigue (67%) Pain symptoms (58%)
Depression (31%)	Fatigue (75%) Psychological symptoms (others) (50%) Pain symptoms (50%)	Depression (56 %)	Fatigue (79%) Psychological symptoms (others) (57%) Pain symptoms (43%)	Appetite loss (80%)	Nutritional impact symptoms (others) (83%) Fatigue (58%) Psychological symptoms (all) and Pain symptoms (33%)
Cough (23%)	Respiratory symptoms (except cough) (100%) Fatigue (67%)	Appetite loss (44%)	Nutritional impact symptoms (others) (64%) Fatigue (36%) Psychological symptoms (all) (27%)	Cough (67%)	Dyspnea symptoms (60%) Psychological symptoms (40%) Respiratory symptoms (except cough) and Fatigue (30%)
Appetite loss (8%)	Nutritional impact symptoms (others) (100%) Fatigue (100%)	Cough (40 %)	Dyspnea symptoms (60%) Fatigue (50%) Psychological symptoms (40%)	Dyspnea (60 %)	Respiratory symptoms (others) (89%) Pain (56%) Psychological symptoms (56%)

Notes. A comparison between a priori and de novo symptom clusters articles regarding commonly occurring symptoms and the most common symptom categories that these symptoms are found clustered with (I). In this comparison here, the symptoms fatigue, pain, and dyspnea are equal to the symptom categories in Table 4 i.e., including several similar items each. The item depression also includes the similar psychological items worry, outlook, sadness, and distress. The item appetite loss does not include any other similar nutritional items. In this table, the percentages refer to how present fatigue, dyspnea, pain, cough and appetite loss were among the particular types of article, and secondly which symptoms it tended to cluster with most frequently.

In Table 4, the symptom categories and their respective included symptom items, are presented to display how the categories were shaped in the review process.

Due to large amount of items attributable to the large number of measurement instruments, related individual symptom items were combined and sorted into these symptom categories to make further comparisons possible.

Table 4. Symptom categories and the items included

Symptom Category	Items Included
Fatigue	Fatigue, drowsiness, lack of energy, weakness, leg weakness, dizziness, tiredness
Psychological symptoms	Anxiety, depression, worry, sadness, distress, outlook, anger, concentration problems, depressed mood, sad, worrying, panic, difficulty remembering/memory problems/remembering things, insomnia, disturbed sleep, poor sleep, sleeping problems, sleeplessness, irritable, confusion, emotional problems
Respiratory symptoms*	Dyspnea symptoms Dyspnea, difficulty breathing, shortness of breath, breathlessness Respiratory symptoms (others) Cough, congestion, expectoration/sputum/mucus, hemoptysis, chest tightness, wheeze, dry/congested nose
Nutritional impact symptoms	Appetite change, appetite loss, weight loss, anorexia, nausea, vomiting, taste- and smell alterations, dysgeusia, sore mouth, dysphagia, sore throat, dry mouth, eating behavior symptoms
Pain symptoms	Pain, neuropathy, numbness, tingling
Elimination/abdominal symptoms	Bowel problems, constipation, edema, urinary problems, bloated, abdominal distension
Body-, skin-, and hair- related symptoms	Itchy/dry/changed skin, hair loss, alopecia, altered appearance, tinnitus, blurred vision

Notes. Related individual symptom items combined and sorted into symptom categories to make comparisons possible.

* When applicable, *Respiratory symptoms* were divided into *Dyspnea symptoms* and *Respiratory symptoms (others)*, as for example both dyspnea and cough could be a part of the same cluster

The patient-reported outcome instruments used and the symptom dimensions measured or described in symptom cluster research

Overall, 36 different validated instruments containing symptom measurements were identified (Table 5). In addition, there were some variations in the Numerical Rating Scale items because this scale was used for several symptoms, such as dyspnea, pain, nausea, and fatigue. Additionally, some unconventional author-developed symptom scales were used. The instruments mainly used were cancer-specific and disease-specific scales, such as the lung cancer modules of cancer-specific instruments. Some symptom-specific instruments were also used. Among the 36 validated instruments, 20 were used in the articles with de novo methodology alone, 4 were used in articles with a priori methodology alone, and 12 instruments were used in both types.

Table 5. Instruments used in lung cancer research in relation to symptom dimensions measured and symptom clusters defined a priori or de novo

Abbreviation	Instrument	Dimensions measured				A priori- article (n)	De novo- article (n)
		Intensity	Timing	Distress	Quality		
AIS	Athens Insomnia Scale	x					1
BFI	Brief Fatigue Index/Inventory	x		x			1
BPI	Brief Pain Inventory	x		x			1
BSI	Brief Symptom Inventory	x					1
CDS	Cancer Dyspnea Scale	x			x	1	2
CES-D	Center for Epidemiological Studies Depression Scale		x				3
CFS	Cancer Fatigue Scale	x		x			1
CSEI	Cancer Symptom Experience Inventory	x	x			1	
DSASS21-A	Depression Anxiety Stress Scales 21 – Anxiety subscale	x				1	
DT & PPL	Distress Thermometer and Physical Problem List		x				1
EORTC QLQ C30	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire	x				3	9
EORTC LC13	European Organisation for Research and Treatment of Cancer – Lung Cancer module	x				2	4
ESAS	Edmonton Symptom Assessment System	x					2
FAACT	Functional Assessment of Anorexia Cachexia Therapy	x					2
FACT-F	Functional Assessment of Cancer Therapy – Fatigue	x				1	1
GAD-7	Generalized Anxiety Disorder-7		x				2
HADS	Hospital Anxiety and Depression Scale		x				3
HADS - D	Hospital Anxiety and Depression Scale – Depression subscale only		x			1	2

LCSS	Lung Cancer Symptom Scale	x				2	2
MDASI	M.D. Anderson Symptom Inventory	x				1	7
MDASI – LC	M.D. Anderson Symptom Inventory – Lung cancer module	x					3
MSAS	Memorial Symptom Assessment Scale	x	x				2
NRS	Numerical Rating Scale	x				2	3
PFS	Piper Fatigue Scale	x	x			2	
PG-SGA-SF	Patient-Generated Subjective Global Assessment – Short Form		x				2
PHQ-2	Patient Health Questionnaire-2		x				1
PHQ-9	Patient Health Questionnaire-9	x	x				2
PRO-CTCAE	Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events	x	x				2
PROMIS	Patient-Reported Outcomes Measurement Information System	x	x				1
SDS	Symptom Distress Scale	x	x			1	4
SF-8	Short Form 8 Health Survey	x					1
SF-12	Short Form 12 Health Survey	x				1	1
SF-36	Short Form 36 Health Survey	x				3	2
STAI	State-Trait Anxiety Inventory	x	x			2	
SQQ	Symptom Query Questionnaire	x					1
TSS	Taste and Smell Survey	x	x				1
VAS	Visual Analogue Scale	x				2	2
-	Various author developed symptom scales or single items	x	x				7

Notes. The total amount of a priori and de novo-approach articles in the final sample were 13 and 40 respectively. The number in the right hand columns indicate in how many articles an instrument was used.

The symptom dimensions, according to TOUS being measured by these instruments, mainly included intensity and/or timing, with only a few containing the distress and quality dimensions. In the qualitative studies, several descriptions were identified within the distress, timing, and quality dimensions but fewer regarding the intensity dimension.

Intensity

Intensity was the most frequently measured dimension, existing in 15 instruments as the solitary measured dimension. Intensity and timing were present in nine instruments, intensity and distress were present in four instruments, and intensity and quality were present in one instrument. The intensity dimension was not so noticeable in the qualitative studies but was described in terms of a symptom being bothersome, offensive, or unbearable.

Timing

Six instruments measured the timing dimension. The qualitative research described this dimension as symptoms that were described as having unpredictable timing, being long-lasting or ever present, and sometimes being related to certain activities and timepoints.

Distress

Four instruments were found to measure both the intensity and distress dimensions. In the qualitative studies, the distress dimension was highly dependent on the patients' experiences and knowledge of the symptoms. Insecurity and novelty of symptoms increased distress, while experience, acceptance, and knowledge caused a lower level of distress. The patients also described how their level of distress was related to how the symptoms affected them in their daily lives.

Quality

Only one instrument was identified to assess the quality dimension. Narratives in qualitative research regarding the quality dimension were patients' physical and location descriptions related to the symptoms, as well as bodily perceptions relating to how the symptoms made them feel.

Study II

The symptom cluster management process – a situational theoretical model

A situational theoretical model (Figure 4) was constructed from the patients' narratives describing their symptom cluster experiences and management strategies from the time of diagnosis and during curative oncological treatment. The circles illustrating the categories and components of the model are not to be regarded as separated, as they influence each other. Viewing the model from inside and out, the core of the model illustrates the main category: 'To get through to survive.' In the next section, six sub-categories related to the category 'Handling symptom clusters' are described, portraying the patients' symptom cluster management strategies. This is followed by the category 'Living with symptom clusters,' described through two sub-categories concerning the outcomes of the symptom cluster experience and management in the patients' lives. The outer circle portrays the impacting conditions that affect both handling and living with symptom clusters.



Figure 4. The model of the process of symptom management, including its impacting conditions, in patients with lung cancer during curative oncological treatment.

The main category '*To get through to survive*' derives from the patients' determination to survive, which was the motivation and goal of their management strategies, as they dealt with symptom clusters in this particular part of the cancer care trajectory. The patients expressed how the current time was essentially only about survival, not living, under these circumstances.

The category '*Handling symptom clusters*' illustrates the patients' symptom cluster management strategies in six sub-categories. Described clockwise in the model, the category includes: (1) *Normalizing and accepting* outlines how the patients accepted symptoms as being a part of the cancer journey, and how they found reassurance and acceptance in that knowledge. Unfortunately, this strategy could also leave symptoms unmanaged or undermanaged, as they rarely, or fairly late, notified a health care professional or asked for support regarding the symptoms. The normalizing strategy was generally also indirectly supported by health care professionals, as discussions regarding many symptoms generated a notion among the patients that 'this is normal' and that symptoms were unavoidable.

Another strategy used by the patients was (2) *Receiving support and guidance* portrays the support to the patients from others, and was described as both positive and negative experiences by the patients. Some appreciated the concern of others and found it helpful to have someone provide help, and some had experienced a lack of understanding and interest, particularly from health care professionals but sometimes also from their spouse or others.

(3) *Reevaluating life and setting limitations* describes how the patients adjusted to their situation by reevaluating what was really important and necessary to them here and now and by prioritizing where to focus their efforts. Some found it supporting, although unusual, to be able to say no and set limitations, as they were used to thinking about others' well-being more than their own, and now it was strengthening to them to be able to say no. (4) *Adapting to a changed ability* portrays how they managed the altered physical, psychological, and emotional functions by listening and adapting to their altered body. They reported feeling better by sometimes choosing not to push

things too far or allowing for more activity during good times. Many adaptations were made due to fatigue, dyspnea, pain, and other debilitating symptoms affecting them negatively, and many of the patients conserved their efforts to the daily treatments with no energy or motivation for anything else. (5) *Performing self-care and taking initiatives* was the category describing how they implemented self-care and took their own initiative regarding seeking information and support to help them manage their symptoms. Often, others, such as family members, friends, or health care professionals, were a part of the symptom management process. Lastly, (6) *Taking one day at a time*, a sub-category named after the particular strategy mentioned by nearly all patients. This was a way of decreasing concerns regarding the future, as they found it difficult to foresee the possibility of symptoms becoming long-lasting or getting worse, or anticipating symptoms not yet experienced. It was also a way of not worrying about their functional losses due to the symptoms.

In the next section of the model is the category *Living with symptom clusters* containing two sub-categories that reflect patients' life situations with symptom clusters and what happened as they went through their treatment and had to manage symptom clusters. This category captures the patient's processes of reasoning around what had changed in their life while living and dealing with symptom clusters and defines the outcomes concerning them as a person and in relation to others.

The subcategory *Experiencing vulnerability* reflects their feelings of being insecure, scared, and lonely, as they were left to deal with their changed physical body and self. The body was no longer trusted to perform in a certain way, which made them feel helpless at times. They expressed grief and sadness over lost functions and the insecurity of knowing what would happen to their functions further on. A sense of loneliness was expressed by some, in the sense that they wanted to portray a stronger self toward others while feeling quite the opposite. Others avoided social situations so that they would not have to show their weaknesses or put up a front, therefore becoming socially distant and more alone. The subcategory *Changing relationships and coherence* portray the changes in their roles and social structures.

Many expressed how they were used to being people with certain skills and competencies, but now they had to receive assistance from others. These changes triggered mixed emotions, sometimes relief and appreciation, and sometimes they felt lost, frustrated, and sad. Some had a partner or friend with whom to share these feelings, but many expressed a sense of loneliness and were unable to talk about these aspects of the illness with others.

Lastly, in the outer circle of the model, the impacting conditions are described. Apart from the described categories, the analysis also identified four conditions affecting the symptom cluster experience and management process, namely '*the self*', relating to factors such as the patients' education, personality traits, and cultural aspects. The type of lung cancer, type of treatment, and co-morbidities associated with physical aspects were defined as '*the body*'. Conditions concerning their employment and relationship status, living arrangements, and access to health care professionals were associated with '*the situation*'. '*The cancer experience*' was also considered to be an important condition, as it existentially shadowed the patients' total life situation and therefore also influenced the experience and management of symptom clusters.

Summary of the results

The symptom cluster experience and the management process among patients with lung cancer are both complex and multidimensional, as these two studies have shown. During the cancer care trajectory, a vast number of symptom clusters may affect these patients. As depicted in these results, symptom cluster research is a scattered area, making conclusions and comparisons difficult. The lack of stringency and methodological issues regarding the measurement and comparison of symptom items and dimensions are made evident, but some patterns could be identified, such as the most prevalent symptoms and their cluster constellation varieties. Fatigue stands out as the main concern.

Through the patients' own accounts, the symptom management process was outlined in how the patients dealt with the many symptoms arising from their illness and treatment and how they were coming to terms with and handling their changed body and altered abilities. Although they often used successful management strategies and had a great deal of self-care capacity, their strategies for symptom cluster management were not always appropriate, timely, or efficient, as they were left to their own devices without appropriate information, validation, support, and guidance from health care professionals. Further, the impacting conditions regarding their individual characteristics and contextual surroundings had a bidirectional relationship with their ability to manage symptom clusters and the consequences of living with them.

Discussion

The overall aim of this thesis was to explore symptom clusters in patients with lung cancer from a subjective perspective before, during, and after oncological treatment. This knowledge and understanding may thereby benefit symptom cluster assessment and management of patients with lung cancer within oncological and cancer care contexts.

The main results show that patients with lung cancer experience many variations of symptom cluster constellations, which have some similarities and differences depending on the methodology. The symptoms are measured by many different instruments, although only one third of the instruments used in the included studies account for the multidimensionality of symptom experience by measuring more than one dimension. Fatigue is the overall predominant symptom measured, followed by dyspnea, pain, cough, depression, and appetite loss in various constellations (I). How patients with lung cancer experience and manage symptom clusters is portrayed in a situational conceptual model, which describes management strategies and the subjective experience, and identifies impacting conditions of the management process *'to get through to survive'* (II).

The lung cancer experience is complex, dynamic, and changing (Fitch, 2019). Since studies I and II commenced, treatment paradigms have evolved to incorporate more immunotherapy, targeted therapies for molecular alterations, and chemotherapy/immunotherapy combinations (Lai-Kwon et al., 2021; Temel et al., 2022), which is important to have in mind reading the findings. Therefore, both researchers and health care professionals should consider these new treatment guidelines in interpreting the results of these studies (I + II) and planning for future studies regarding symptom clusters and symptom cluster management, as the profiles of patients receiving the oncological therapies may differ from those of this thesis' population.

Discussion of the results

Descriptions and variations of symptom cluster constellations

The diversity in symptom cluster research regarding patients with lung cancer was presented in the scoping review (I), in which a great diversity of symptom cluster constellations was displayed. The understanding of symptom clusters may benefit from further comparisons between de novo and a priori approaches (Xiao, 2010), and these findings indicate cluster differences depending on the approach. The majority (n = 40) of the 53 included articles explored symptom clusters defined de novo, and the others (n = 13) used the a priori approach. The symptom clusters investigated by the two approaches differed in content regarding the number of symptoms in their constellations and the symptom items included in the various clusters. Some differences were revealed by the comparison of a priori and de novo symptom clusters regarding commonly occurring symptoms. In de novo clusters, there was a greater occurrence of nutritional impact symptoms, pain, cough, and depression compared to the a priori clusters. In the comparison regarding other symptoms that clustered with these most prevalent symptoms, there were also differences identified depending on the approach (I). With the a priori-approach, the symptom clusters investigated have been based on symptoms which have demonstrated moderate-high correlations in previous studies (Ward Sullivan et al., 2018). Although both the number of symptoms in an a priori cluster and the number of clusters investigated may have to be limited to a few for methodological reasons, the results from this thesis could warrant further consideration of the selection of symptom items in a priori clusters and additional studies to define symptom clusters de novo. As the distress-dimension is rarely measured (I), the symptom cluster research based on the intensity and timing-dimensions may not be entirely clinically relevant, as it does not consider the patients' holistic symptom experience. Also, qualitative studies are required to ensure that the symptom clusters evaluated are appropriate and empirically defined to further guide symptom management (Barsevick, 2016).

Some evidence suggests that the number and composition of symptom clusters remain relatively stable over time (Miaskowski et al., 2017;

Rha & Lee, 2019), and symptom clusters have also been found to be stable across instruments and different methods of analysis (Aktas et al., 2014; Hensch et al., 2009). Although this study (I) included a large and diverse population of patients with lung cancer, some clear patterns of clustering could be identified, which supports the clinical importance of the assessment and management of symptom clusters. As new treatment options are becoming available, further symptom cluster research is required to investigate their patterns of symptom clustering, which are likely to differ from those described in the current literature on traditional treatments, such as chemotherapy and radiotherapy. Most studies included (I) were cross-sectional, but the few studies with several measurements over time indicated a certain stability of clusters over time, which makes these patterns interesting to explore further in longitudinal studies. The vast majority of symptom cluster research so far has focused on identifying clusters. Studies that investigate how to assess symptom clusters regarding symptom dimensions and their impact on patient-reported outcomes are lacking, as well as studies exploring the meaning and significance of the symptom experience.

Fatigue was the overall most prevalent symptom among patients with lung cancer (I), followed by dyspnea, pain, depression, appetite loss, and cough, which has been described in other studies (Carnio et al., 2016; Henschall et al., 2019; Koch et al., 2021; Lee, 2020). In general, fatigue stands out among all other symptoms as the main area of concern, as it affects patients' function and health-related quality of life negatively for a long period of time. Relative to depression and anxiety, fatigue also has more negative effects on health-related quality of life (Jung et al., 2018). Comparing patient groups over time, patients with lung cancer actually presented positive trends regarding mental health, although physical health outcomes were unchanged (Allaire et al., 2024), possibly due to the increased treatment options offering a brighter future regarding survival but confirming that fatigue and other more physical concerns are still evident.

In this thesis, the multidimensional aspects of symptoms, such as fatigue and pain, have been considered, but they are defined as one symptom in the data analysis (I). This may pose a challenge regarding

measurement and management, depending on whether fatigue is considered one symptom or two separate phenomena: physical fatigue and mental fatigue (de Raaf et al., 2013). To measure cancer-related fatigue, the European Society for Medical Oncology (ESMO) guidelines (Fabi et al., 2020) suggest a 10-point numeric rating scale for fatigue as the best screening tool. However, the use of a more specific questionnaire, such as the Brief Fatigue Inventory (Mendoza et al., 1999), to assess moderate to severe fatigue would be beneficial, as the assessment includes intensity as well as impact on daily life regarding interference with mood, relations, walking ability and enjoyment of life. As described in the revised Wilson and Cleary model (Ferrans et al., 2005), HRQOL is important to consider when assessing symptoms' impact on the patients' life, and further use of HRQOL measurements can be clinically meaningful and assist in decision making and guidance of oncological care (van der Weijst et al., 2017). In cancer care, a screening tool that captures multiple symptoms may also be of clinical value, since fatigue often occurs with related symptoms. There is no clear recommendation regarding the most appropriate subjective measure, indicating the need for comparable data to reliably detect changes over time (Fabi et al., 2020).

In study I, appetite loss was selected as the nutritional impact symptom for comparison because it may affect the patient during a greater part of the cancer care trajectory. The symptom has a multifaceted effect on the patients', considering the actual weight loss related to eating less, the social aspects of not being able to eat normally, and the existential dimension of having to eat to survive. Nausea and vomiting are not uncommon symptoms in clusters, but they may be more temporal in nature in relation to chemotherapy and/or radiotherapy, and regularly updated guidelines regarding antiemetic prophylactic drugs (Ruhlmann et al., 2023) provide clinically relevant recommendations to prevent or decrease these symptoms during oncological treatment, which has significantly decreased these side effects in recent years. Nutritional screening and supportive care are likely of great significance in symptom management, as well-nourished patients experience better HRQOL, lower overall symptom burden, and better health-related outcomes and prognoses (Gul et al., 2021; Kiss, 2016; Polański

et al., 2017; Polański et al., 2021). Therefore, it is worrying that nutritional impact symptoms are not very common in a priori symptom cluster research, but they are much more present in de novo research (I).

The lung cancer experience is complex, dynamic, and changing (Fitch, 2019). Since studies I and II commenced, treatment paradigms have evolved to incorporate more immunotherapy, targeted therapies for molecular alterations, and chemotherapy/immunotherapy combinations (Lai-Kwon et al., 2021; Temel et al., 2022), which is important to have in mind reading the results. Therapies that are more recent have different action mechanisms and side effects compared with older standard therapies, as changes occur in the relationships and interconnections between and among symptom clusters, depending on treatment and the time point of measurement (Kalantari et al., 2022). Therefore, both researchers and health care professionals should consider these new treatment guidelines in interpreting the results of study I. However, the key symptoms of fatigue, distress, and appetite loss appeared among the five symptom clusters discovered in a study of symptom clusters in patients with lung cancer who were treated with immunotherapy (Zhang et al., 2022), which is comparable to the results of study I.

The patient-reported outcome measures (PROM) instruments used and symptom dimensions measured

In study I, the 47 articles that used quantitative/mixed methods involved a large number of different symptom assessment instruments, and a few nonconventional authors developed instruments for measuring intensity alone or in combination with timing. Similar to findings of Damm et al. (2013), the EORTC QLQ-C30, along with the lung cancer specific module LC13, was found to be the most frequently used instrument (I). Whether a measurement is employed within a clinical or research context and when and by which instrument the symptom assessment is conducted affect the accuracy and relevance of the measurement. Patients may score high on intensity but may not be so bothered by that symptom because the timing dimension may be limited or their knowledge and means of managing make it controllable. Conversely, a lower-intensity symptom may be more incapacitating

because of distress and quality aspects (Lenz et al., 1997), which may be problematic when some studies have a certain cut-off point for inclusion regarding intensity. It has also been identified that patients report symptoms that health care professionals might not consider until they reach a higher level of severity (Atkinson et al., 2017). In the clinical cancer care setting, structured symptom assessments and supportive symptom management should be integrated into cancer rehabilitation care, yet the entire symptom experience may not be captured and understood unless the patient is actually listened to (Henoch et al., 2018).

When studying the multidimensional symptom cluster experience, TOUS can provide a clinically relevant conceptual mapping of the symptom dimensions and suggest how and why they are important to measure for clinically useful research. The restriction of measuring an individual dimension is considered inadequate, and it is recommended that each symptom be measured separately using multidimensional measures (Lenz et al., 1997). Symptom dimensions should also be considered important when developing and evaluating symptom management strategies, not just for the assessment itself (Dodd et al., 2001; Bender et al., 2018). The use of multidimensional scales to measure the complex nature of a symptom cluster was suggested by Barsevick et al. (2006), but these results (I) indicate the methodological issues in measurement and comparison of symptom items and dimensions due to the vast number of instruments used and the absence of multidimensional assessments within the lung cancer context alone. There is a need to further evaluate the validity, reliability, and sensitivity of PROM instruments in symptom cluster research (Miaskowski et al., 2017) because this stringency is still missing, making comparisons and evaluations of results difficult.

In the scoping review, the most commonly measured dimension among the quantitative studies was the intensity dimension. However, intensity was not the most prominent dimension from the patients' perspective in the qualitative studies (I). In study II, the distress, timing, and quality dimensions were more evident in the patients' narratives than the intensity, even though study II did not investigate the symptom dimensions *per se*.

The quantitative data from the SAS-LC (II) showed that fatigue, breathlessness at exertion, pain, insomnia, and cough had the highest scores on both intensity and distress, which correlated with the findings of common co-occurring symptoms from study I.

The validity and usefulness of the situational theoretical model for symptom cluster management

The symptom cluster management process from the patients' perspective is presented in a situational theoretical model describing the categories, including the closely related impacting conditions and consequences. Through the patients' narratives, '*To get through to survive*' emerged as the main category (II), illuminating the ongoing process of the patients' actions and reasoning during this part of their cancer care trajectory.

Very few previously published qualitative studies have explored the symptom management process among this particular population. Thus, the results from study II may now portray how patients deal with the many symptoms arising from their illness and treatment and how they come to terms with and handle a changed body and altered abilities. An understanding of the patients' experience and perspective is essential to providing high-quality, person-centered care.

The situational theoretical model describes how patients' strategies become altered as they gain knowledge and experience. Before being diagnosed with lung cancer, some patients had long experience with bothersome symptoms, such as cough and dyspnea due to smoking and/or chronic obstructive pulmonary disease, or tiredness and pain related to chronic pain conditions. Other patients had no symptoms at the time of diagnosis and were therefore more inexperienced in handling such symptoms. Hence, the patients brought different knowledge and experiences into their situations, which affected their management strategies (II).

Further, the influential conditions regarding their contexts and concerns of physical and psychological origin affected their abilities to handle symptom clusters (II), similar to the bidirectional relationships

of the components of TOUS (Lenz et al., 1997). Although the findings showed that the patients were often capable of applying many successful management strategies and had a great deal of self-care capacity, their self-care strategies in symptom cluster management were not always appropriate and efficient, as they were left to their own devices without appropriate information, support, and guidance from health care professionals. Sometimes unknowingly, they would therefore risk bearing a larger symptom burden or longer rehabilitation due to ineffective interpretations and strategies. The patients often felt unsure of whether and when to report certain symptoms that could have a detrimental effect on their health. Further, when they did voice their concerns, they did not always feel validated or listened to, and they sometimes perceived health care professionals as disease-focused instead of person-centered (II).

The patients' inefficient symptom management strategies (II) could be an indication of a non-optimal level of health literacy. Health literacy involves the application of a variety of skills to access, comprehend, evaluate, communicate, and act on health-related information (Poureslami et al., 2017). Oncology nurses should therefore consider the patients' health literacy level as an important factor (Agre et al., 2006) affecting the symptom cluster management process. The early descriptions of health literacy focused mainly on patients (Nutbeam, 2000), but more recent conceptualizations involve health care providers as a key component, as they have a great responsibility regarding the exchange of health-related information (Rudd, 2010) by ensuring appropriate information is made available (Coleman et al., 2017) and understood.

In cancer care, it is necessary to understand patients' perceptions and ways of reasoning to ensure that they are provided with adequate support to reach the best possible outcome, not only survival (II). As these patients continue to experience a significant symptom burden, improved symptom management strategies supported by health care professionals in a holistic approach are deemed to be vital to improving the level of symptom distress and quality of life among these patients (Sung et al., 2017), as adequate symptom management is considered

essential for maintaining functional status and health-related quality of life (Ferrans et al., 2005).

The World Health Organization highlights the person-centered care approach as a key element of good quality care in health services (World Health Organization, 2013, 2015), and Swedish cancer care is strongly aligned with general person-centered developments within the health care system. This ethical approach to care emphasizes a holistic view of the person, one that focuses on their needs, strengths, and weaknesses (Ekman et al., 2011). Contact nurses in cancer care are specifically assigned to inform and support patients and their families in a holistic manner throughout the cancer care trajectory. Supportive care guided or led by nurses in cancer care can be provided on a group or individual level and includes emotional and practical support, education and information, and social and/or physical activities (Charalambous et al., 2018). By detecting gaps through focusing on the patients' experiences, facilitators and inhibitors of the symptom management process may be identified as targets for interventions and improvements (Yannitsos et al., 2022), and appropriate person-centered nursing interventions may be developed (Magalhaes et al., 2020). The situational theoretical model (II) could therefore be used by contact nurses and other health care professionals to better support the patients and their families by assessing and increasing health literacy and improving their symptom management strategies.

Methodological considerations

Study I

The scoping review gives width and possibilities in its methodology, but it is a challenge to summarize when the final sample is large. The original plans for the review process, as stated in the published protocol (Karlsson et al., 2020), were developed by dividing the research questions into two parts. Part 1 was presented in this scoping review, and part 2 focusing on the influencing factors and outcomes of the symptom cluster experience will be presented as a separate study. Methodological rigor was shaped by involving two to five team members in the five steps (Arksey & O'Malley, 2005), supporting a systematic and transparent review process. No limitation was set

regarding the earliest year of publication, as co-occurring related symptoms were investigated earlier than the concept of symptom clusters was introduced. A limitation to more current years could have decreased the final sample but would have omitted important findings. Although lung cancer is a divided group of many subtypes (Travis et al., 2015), and the incidence, mortality, and therapy options vary between subtypes (Howlader et al., 2020), this review included a wide population with no limitation to specific subtypes or in terms of the phase of the cancer care continuum: before, during, or after treatment. This may affect the occurrence of specific symptom clusters, depending on when the symptoms and dimensions have been measured. The research questions did not include the methodological approaches regarding the statistical methods used (I), which may have provided additional knowledge regarding the most appropriate analytical method to create symptom clusters and awareness concerning common and unique underlying mechanisms of symptom clusters (Ward Sullivan et al., 2018). TOUS provided direction regarding the categorization of symptom dimensions when describing the PROM instruments, but these interpretations of the dimensions may not equate to others' interpretations.

Study II

Although a small population, the results can be considered representative for the group in focus.

The findings are to a certain extent influenced by the COVID-19 pandemic, as five patients were interviewed before COVID-19, while the other ten were interviewed during the pandemic, which affected society as a whole but the health care system in particular, with lockdowns and restrictions. The encouraged distance-keeping between people and the protective gear they and the health care professionals had to wear may have been perceived as a communication barrier.

The long interval between the interviews and the different interviewers engaged during the data collection may have affected the results. This was due to the study being part of a larger symptom management project with several simultaneous data collections in progress. Nevertheless, the prerequisites were the same for all participants, apart from the COVID-19 restrictions that applied to two thirds of the participants.

The interview guide was modified during the analysis after six interviews to further focus on the symptom management process, and additional few adjustments were made to capture rich data regarding the emerging categories as the analysis continued. The data were kept in the original language (Swedish) during the analysis and translated at the end of the process so as not to lose accurate meaning in translation.

The SAS-LC symptom assessment scale was used to encourage the patients to reflect on current symptoms and how bothered they felt by the symptoms. The discussion between the participant and interviewer while going through the assessment scale was therefore recorded as part of the interview session to ensure that the data were not lost. It also served as a prompt for the patients to bring up problems and symptoms not mentioned during the interviews. The SAS-LC was modified from the original symptom assessment scale (Langegård et al., 2021) by the authors in 2019 (II); therefore, the two interviews from 2017 lacked these added items. The original version did not contain the specific respiratory symptoms of cough, hemoptysis, or breathlessness at exertion/rest, which are relevant for this population; therefore, these items were added (II). Although there are issues regarding stringency in symptom cluster research, scholars have suggested that disease-specific measures to evaluate symptom clusters should be developed (Miaskowski et al., 2017), and the SAS-LC will be used in future SyCL studies.

The credibility of this study was supported by a structured approach regarding data collection and analysis, and via the use of COREQ criteria (Tong et al., 2007). As there are few previous studies in this context and population, the originality of this study is salient. The resonance of the study was strengthened by having the entire team involved in the data analysis. Using the theoretical framework as guidance when in doubt ensured that codes and subsequent categories were focused on symptoms and not the cancer experience as such. To some extent, it may be unavoidable that the findings reflect the experience of being diagnosed and living with cancer, as the symptoms experienced could be shadowed by that of the total cancer experience, and both may not be fully separable. The intention was to focus on the data correlated

to the complex symptom management process, and because TOUS has been used extensively in oncology and symptom cluster research (Blakeman, 2019), it was recognized as useful for this study.

Regarding usefulness, the situational theoretical model developed from these findings is specific to this particular population and context (II), but patients' need for person-centered support during the cancer care trajectory and concerning symptom cluster management in particular may apply to many other patients with cancer and other chronic illnesses. Many patients with lung cancer will continue to receive the types of treatments as the patients in study II; therefore, this model may apply to several clinical practices within oncology worldwide. To understand the symptom cluster phenomenon and related health behaviors and to improve symptom management among patients with cancer, the use of key concepts and theoretical models is important (Salveti & Sanchez, 2022). By using symptom models and theories, symptom management research can be adapted to clinical use by tailoring interventions based on patients' personal characteristics and the characteristics of symptoms (Brant et al., 2010).

A limitation is the inclusion of Swedish-speaking informants only, and therefore a lack of a wider ethnic and cultural context. Further, patient recruitment was only possible from one regional hospital, as the planned recruitment at a larger cancer center was hindered by COVID-19 limitations.

Conclusions

There is an abundant variety of symptom clusters among patients with lung cancer. The symptom clusters defined a priori and explored de novo differ in content regarding symptoms and the number of symptoms in their constellations. Overall, fatigue is the predominant symptom and is found to most frequently co-occur with other symptoms in clusters. Markedly, the a priori clusters often contain dyspnea more often, while the de novo clusters often contain pain, cough, depression, and nutritional symptoms. The qualitative studies reviewed in this thesis complement the findings from the included quantitative studies, endorsing the presence of clinically significant symptom clusters among patients with lung cancer and contributing evidence regarding the quality dimension that is missing in most symptom assessment instruments.

The results show that living with symptom clusters is more about survival than actually living. Patients often feel left to their own devices to deal with symptom clusters and may not understand or foresee problematic circumstances as they manage their situations on a day-to-day basis. As many symptoms are regarded as unavoidable or normal and as an integrated part of the illness and treatment, patients do not ask for support, and they often experience that the support offered to them is insufficient.

Their management strategies would sometimes be efficient, and sometimes not. The patients struggled to evaluate their symptoms, and therefore sometimes unknowingly risk gaining a larger symptom burden or longer rehabilitation due to ineffective interpretations and strategies.

Implications for practice

The importance of considering the multidimensional aspects of the symptom cluster experience is highlighted to sustain a holistic approach in research and cancer care (I + II).

Fatigue is the overall most prevalent symptom in clusters, indicating a specific area of concern in symptom management, as fatigue may significantly impair all dimensions of health-related quality of life (I). Fatigue, psychological symptoms, and nutritional impact symptoms often co-occur and are an important area of interest for oncology nursing and symptom management interventions (I).

Timely and continuous symptom recognition, assessment, and management are required to address distressing symptom clusters and ensure that preventative, educational, and adequate support is provided in a team approach during the cancer care trajectory (II).

Health care professionals, particularly oncology nurses and contact nurses, should consider the peril of normalizing symptoms. Although some symptoms due to illness and/or treatment may be unavoidable and, to some extent, may be considered 'normal,' this must not be a reason to accept inadequate symptom cluster assessment and management (II).

The patients' altered time perspective that stems from the approach of living one day at a time needs to be considered in regard to patient education and the further development of person-centered care for this population (II).

Patients with lung cancer should be encouraged to participate more in their own care and become more involved in peer support and advocacy (II).

Future research

Fatigue, psychological symptoms, and nutritional aspects are emphasized as important areas for further research to improve symptom cluster management for patients with lung cancer. Intervention studies that consider aspects from several stakeholders—that is, patients, family, health care professionals, and researchers—are required to advance adequate symptom cluster management.

There is a need for further knowledge regarding barriers and facilitators regarding symptom cluster management from patients', family members', and health care professionals' perspectives. Due to the differences between symptom clusters related to the *a priori* or *de novo* approach, future symptom cluster research should consider this further. Specifically nutritional impact symptoms are necessary to consider further as they are likely to have a synergistic effect regarding fatigue. In addition, studies that investigate how to assess symptom clusters regarding symptom dimensions and their impact on patient-reported outcomes are required.

Research regarding symptom cluster assessment and management should mirror the progress in treatment options for patients with lung cancer. In clinical trials and in clinical contexts, it is vital to consider not only survival rates as primary outcomes but also the subjective experience of these patients and their supportive care concerns. Patients with lung cancer should be able to live during their oncological treatment, not just survive.

Given that certain symptoms are more likely to cluster than others, future research regarding the potential underlying biologic etiology by measuring specific biomarkers could be valuable.

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Appendix

SYMPTOMSKATTNING - LUNGCANCER

Kod: _____
Datum: _____

Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (□□□□) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○) som graderar betydelsen.
Eller sätt ett kryss under **Ej aktuellt**.

	A				B				
	SÅ HÄR VAR DET FÖR MIG				SÅ HÄR BESVÄRANDE VAR DET FÖR MIG				
	Inte alls	Lite	En hel del	Mycket	Av litet eller inget besvär	Av ganska stort besvär	Av stort besvär	Av allra största besvär	Ej aktuellt
Har du under det senaste dygnet									
1. varit trött/kraftlös?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
2. haft svårt att sova?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
3. haft ont?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
4. känt aptitlöshet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
5. haft andningssvårigheter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
6. haft problem att tänka klart eller minnas?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
7. känt dig orolig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
8. haft ångest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
9. mått illa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
10. känt dig ledsen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
11. varit förstoppad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
12. haft diarré?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
13. haft besvär från huden inom det strålbehandlande området?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
14. haft hosta?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
15. haft blodiga upphostningar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
16. känt dig andfådd i rörelse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
17. känt dig andfådd i vila?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
Andra symtom du haft under det senaste dygnet, ange nedan									
18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
19.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>
20.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>



Exploring symptom clusters in patients with lung cancer

This thesis explored symptom clusters in patients with lung cancer before, during and after oncological treatment. A literature review and an interview study was used to explore the symptom cluster experience from the patients' perspective. A large diversity of symptom cluster constellations were identified, in which fatigue was the most commonly occurring symptom, followed by dyspnea, pain, depression, cough and nutritional impact symptoms. Many symptom assessment instruments were identified, measuring mostly the intensity-dimension alone or in combination with timing. The results also stress that living with symptom clusters during treatment is more about survival than actually living. Patients' symptom management strategies were shaped by impacting conditions such as knowledge and earlier experience of symptoms. Symptoms were often regarded as unavoidable by the patients and something to accept. How symptoms were recognized by health care professionals further added to the normalization of symptom clusters. Subsequently, patients would not always ask for support, and their quality of life was negatively affected. Holistic person-centered care including multi-dimensional symptom assessment is considered essential to ensure adequate symptom cluster management for patients with lung cancer.

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