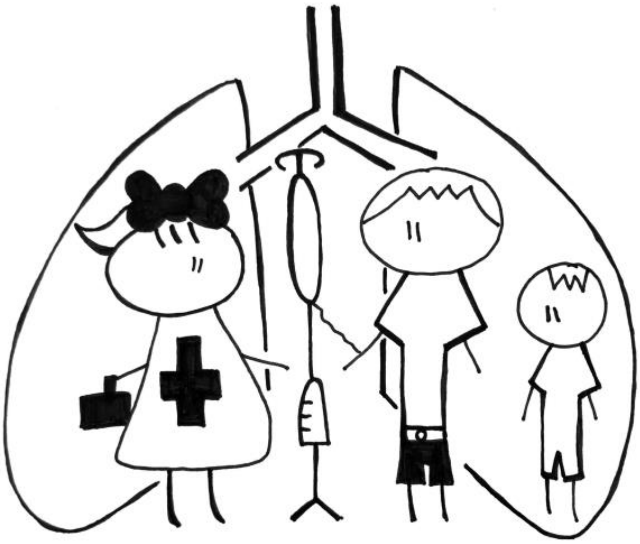
End-of-life discussions during palliative chemotherapy

PhD thesis

Tine Møller Ikander

2021



UNIVERSITY OF
SOUTHERN DENMARK

PhD thesis

End-of-life discussions during palliative chemotherapy

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Funding

The Danish Cancer Society

Region of Southern Denmark

Aage Theodor Larsens Fund of Cancer Research

REHPA, the Danish Knowledge Centre for Rehabilitation and Palliative Care

Research Unit, the Department of Oncology, Odense University Hospital

AgeCare, Academy of Geriatric Cancer Research

Preface

This PhD thesis is based on three studies. All studies were conducted during my employment from 2018-2021 at the Department of Oncology at Odense University Hospital and the Faculty of Health Sciences, University of Southern Denmark. The studies combine quantitative and qualitative data.

- Study 1, a prospective longitudinal study, investigating differences in treatment expectations and quality of life among patients with thoracic cancer aged <70 and ≥70 years who were receiving palliative chemotherapy. The study also investigated family caregivers' expectations of palliative chemotherapy.
  Paper 1:
  Ikander T, Jeppesen SS, Hansen O, Raunkiær M, Dieperink KB.
  Treatment expectations and quality of life during palliative chemotherapy among patients and family caregivers affected by thoracic cancer: A longitudinal prospective study.
  BMC Palliative Care. 2021 Feb 26; 20(1):37.

- Study 2, a systematic integrative review, investigating current evidence of nurses' involvement in end-of-life discussions with incurable cancer patients and their family caregivers.
  Paper 2:
  Ikander T, Hansen O, Raunkiær M, Dieperink KB.
  Nurses' involvement in end-of-life discussions with incurable cancer patients and their family caregivers: An integrative review.
  Palliative & Supportive Care. 2021 May 6:1-12. Doi: 10.1017/S1478951521000596. Epub ahead of print. PMID: 33952373.

- Study 3, a phenomenological hermeneutic study, investigating current practice for end-of-life discussions from the perspective of patients with incurable lung cancer, their family caregivers and nurses.

  Paper 3:
  Ikander T, Dieperink KB, Hansen, O, Raunkiær M.
  Patient, family caregiver, and nurse involvement in end-of-life discussions during palliative chemotherapy: a phenomenological hermeneutic study
  Accepted for publication in Journal of Family Nursing 27.06.21.

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Additional works and contributions to scientific conferences

Additional works – related to the thesis

Ikander T, Jeppesen SS, Hansen O, Raunkiær M, Dieperink KB.
Patienter har høje forventninger til hvad de kan opnå med pallierende kemoterapi.
Best Practice. April 2021.

Additional works – unrelated to the thesis

Dieperink KB, Ikander T, Appiah S, Tolstrup LK.
The cost of living with cancer during the second wave of covid-19: A mixed methods study of Danish cancer patients' perspectives.
Journal of European Oncology Nursing. 2021 Apr 18; 52:101958. Doi: 10.1016/j.ejon.2021.101958. Epub ahead of print. PMID: 33878634.

Ikander T, Hoeck B.
Når alvorlig sygdom flytter ind – omsorg for pårørende.
Klinisk Sygepleje, 34(1), 43-52. 2020

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REHPA, Videncenter for Rehabilitering og Palliation. Projektprogram "Beslutninger ved og om livets afslutning". Projektbeskrivelse og resultater for delprojekt 1: En kortlægning af nationale og udvalgte nordiske og europæiske lovgivninger, guidelines m.v**.** Lokaliseret d. 18.02.21 på: https://www.rehpa.dk/wp-content/uploads/2019/11/Resultater-for-delprojekt-1-En-kortlægning-af-nationale-og-udvalgte-nordiske-og-europæiske-lovgivninger-guidelines-m.v..pdf

Contributions to scientific conferences

Oral presentations

Dieperink KB, Bauer EB, Ikander T, Krause PK, Østervang C, Tolstrup LK.
Writing Cave – COVID-19 gave rise to a new method to focus the research writing process. Nordic Conference in Nursing Research Denmark. October 4-6, 2021.
Accepted for oral presentation

Ikander T, Jeppesen SS, Hansen O, Raunkiær M, Dieperink KB.
High treatment expectations in palliative chemotherapy among patients and family caregivers affected by thoracic cancer: A longitudinal prospective study. 15th International Family Nursing Conference. Virtual, July 30, 2021.

Ikander T, Jeppesen SS, Hansen O, Raunkiær M, Dieperink KB.
Treatment expectations in palliative chemotherapy among patients and family caregivers affected by thoracic cancer. Research Week, University of Southern Denmark, Odense University Hospital, Odense, October 6-8, 2020.
Invited for oral presentation (Cancelled due to Covid-19)

Ikander T, Jeppesen SS, Hansen O, Raunkiær M, Dieperink KB.
High treatment expectations in palliative chemotherapy among patients and family caregivers affected by lung cancer: A longitudinal prospective study. 6th Nordic Conference on Family Focused Nursing, Stavanger, June 2020.
Invited for oral presentation (Cancelled due to Covid-19)

Poster presentations

Ikander T, Raunkiær M, Hansen O, Dieperink KB.
Nurses' involvement in end-of-life discussions with cancer patients and their family caregivers: An integrative review. 17th World Congress of the European Association for Palliative Care (EAPC), Virtual, October 2021.
Accepted for poster and video presentation

Dieperink KB, Ikander T, Appiah S, Tolstrup LK.
The cost of living with cancer during the second wave of covid-19: A mixed methods study of Danish cancer patients' perspectives. Danske Kræftforskningsdage, August 2021
Accepted for E-poster presentation

Ikander T, Hansen O, Raunkiær M, Dieperink KB.
Expectations of palliative treatment in patients with lung cancer and their relatives. 16th World Congress of the European Association for Palliative Care (EAPC), Berlin, May 23, 2019.

Acknowledgements

The last three years have been an exciting journey. A journey that would not have been possible to go through alone. All the way, some special persons supported me, and for this, I will always be grateful.

First, I am truly grateful to all patients and families who participated and who were willing to open up and share their thoughts in a vulnerable time of their life. Without you, this PhD study would not have been possible.

I am also grateful for the funding I received from The Danish Cancer Society, The Region of Southern Denmark, Academy of Geriatric Cancer Research (Age Care), REHPA - The Danish Knowledge Centre for Rehabilitation and Palliative Care, The Research Unit at the Department of Oncology, Odense University Hospital and Aage Theodor Larsen Fund of Cancer Research.

A huge thanks to my supervisor team: Karin Brochstedt Dieperink, my main supervisor. Thank you for all your time and support and for being available 24/7 for questions. You have truly taught me that, anything is possible with hard work. Mette Raunkiær, my co-supervisor. I cannot thank you enough for all you support and for feeding me with your enormous knowledge and experience in qualitative research and palliative care. Thank you, for always seeing the person behind the project, and for helping in every possible way. Olfred Hansen, my co-supervisor. With your vast knowledge on lung cancer and treatment, you have been a great support. Thank you for always believing in me. A special thanks to Stefan S. Jeppesen, for stepping up when I needed it. Thanks for all your help, time and patience when introducing and teaching me about quantitative research and statistical methods.

Thanks to my wonderful PhD colleges, in “Barakken”, both former and present, for inspiring discussions and for being there in both good and difficult times.

A warm thanks to REHPA, for allowing me to be part of an inspiring research team. A special thanks to the “The PhD group”. It really has been a pleasure to meet and discuss all aspects and challenges in being a PhD student.

A heartful thanks to my PhD colleague from REHPA Karen Stølen, for many inspiring and encouraging talks and for always just being a phone call away.

A special thanks to my dear friend Lesley McCartney, for all your time when proofreading the thesis.

Finally, a heart full thank to my friends and family, for encouragement and interest in my PhD life.

I am grateful in my heart to my Mum and Dad for helping in any possible way in the final run. To my husband Peder: Without you, I would never have had the courage to jump on this journey. You never doubted me – and to my loving 3 year old daughter Ea: You made it possible for me to complete the journey I started.

Tine Ikander, 2021

Abbreviations

ACP	Advance Care Planning
DMCG-PAL	Dansk Multidisciplinær Cancer Gruppe for Palliativ Indsats
IFNA	The International Association for Family Nursing
K.B.D.	Karin Brochstedt Dieperink
Lung cancer	Non-small-cell lung cancer, small-cell lung cancer
QoL	Quality of Life
NSCLC	Non-Small-Cell Lung Cancer
REHPA	The Danish Knowledge Centre for Rehabilitation and Palliative Care
SCLC	Small-Cell Lung Cancer
SDM	Shared Decision Making
TNM	Tumours-node-classification system
Thoracic cancer	Non-small-cell lung cancer, small-cell lung cancer and mesothelioma
T.I.	Tine Ikander
M.R.	Mette Raunkiær

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Overall aim

The overall aim of this PhD study was to gain knowledge about expectations, quality of life (QoL) and end-of-life discussions (See “Conceptual framework” on page 21 for definition of end-of-life discussion) in patients diagnosed with incurable thoracic cancer during their course with palliative chemotherapy. The PhD study included the perspective of both patients, family caregivers and nurses.

Background

Thoracic cancer and oncology treatment

Non-small-cell lung cancer (NSCLC), small-cell lung cancer (SCLS), (mentioned in this thesis as lung cancer) are one of the most common cancers worldwide among both men and women [1]. Mesothelioma is a more rare type of cancer, although the incidences are increasing worldwide [2]. Common for NSCLC, SCLC and mesothelioma (mentioned in this thesis as thoracic cancer), is the fact that they have a poor prognosis and a rapid growth [2, 3]. This is also why we chose to include those three diagnosis in this thesis, as the patients and their family caregivers within a short timeframe need to make several decisions related to for example treatment, future care and wishes for end-of-life.

In 2018, n=4791 patients were diagnosed with NSCLC or SCLC, and n=138 patients were diagnosed with mesothelioma, in Denmark [4, 5]. Five-year relative survival for men diagnosed NSCLC and SCLC in Denmark are 19.5% and among women 26.8% [4] and those with mesothelioma have a five-year relative survival of 10.7% for men and 8.1% among women [5]. Patients diagnosed with NSCLC, SCLC and mesothelioma are often represented with many symptoms among others fatigue, pain, loss of appetite, cough, dyspnoea and insomnia [2, 6]. The literature reports, that patients with incurable lung cancer have a median of nine symptoms, with among others pain and dyspnoea as the most common [6]. A large number of patients with thoracic cancer must recognise that they are not curable, mentioned in daily practice is that the cancer is incurable or at an advanced stage [7]. Before initiating any treatment, staging is vital when understanding the extent and prognosis of the cancer [7]. The staging follows the tumours-node-classification system (TNM), which is a standard system for most cancer and also one of the most used staging systems worldwide [7]. The TNM categorises and divides the cancer into local disease, disease with lymph node metastasis and patients with distant metastases (advanced disease)[8]. Around 85% of newly diagnosed patients with lung cancer are diagnosed with NSCLC and hereby around 50% have incurable disease at the time of diagnosis [9], and 15% of the patients with lung cancer are diagnosed with SCLC were 2/3 of those patients have incurable disease at the time of diagnoses [9]. Among 75% of the patients diagnosed with mesothelioma have incurable disease at the time of diagnosis [10]. For the patients included in this PhD study, all are diagnosed with incurable cancer were the cancer have grown into the nearby tissue and may even have spread to other parts of the body, and unlikely to be cured.

Patients diagnosed with incurable thoracic cancer, are often offered palliative treatment, which can compromise both radiotherapy, chemotherapy, immunotherapy or a combination [10, 11]. In the process of planning this PhD study in 2017, treatment with immunotherapy was only about to be implemented in the treatment regimens at the Department of Oncology, at Odense University Hospital (OUH) in Denmark. Furthermore, patients receiving radiotherapy have some other cadences in their treatment and therefore a decision was made to only include patients with thoracic cancer receiving palliative chemotherapy. In a Danish setting, there is a lack of data on the exact number of patients with incurable thoracic cancer receiving palliative chemotherapy due to insufficient reporting [12]. However, The Danish Lung Cancer Register reports that of patients diagnosed with lung cancer in 2018, 36% received curative intended treatment [12], and in light of this, it is assumed that a high number of patients receive palliative intended treatment, even directly after diagnosis.

Palliative care as an integral part of oncology practice

Traditionally palliative care has been provided late in the course of disease after withdrawing palliative intended treatment [13]. (See the section "Conceptual Framework" on page 21 for definition of palliative care). However, in Denmark, as well in other countries, integration of early palliative care into oncology have gained more attention [14]. See **Figure 1** for an illustration of "Traditional Palliative Care vs Early Palliative Care"**.** The figure shows an illustration of the traditional way of providing palliative care, where the palliative care is first initiated when there are no more treatment options. Following an illustration of the early palliative care approach, which illustrates that palliative care should be provided alongside life-prolonging or curative treatment. The Danish Health Authority states in their Recommendations for patients with incurable cancer and other life-threatening diseases, from 2017, that palliative care should be initiated early in the course of treatment and be provided alongside treatment [15]. This is to relieve suffering from both treatment and disease and should be initiated to help maintain a normal life, as much as possible.

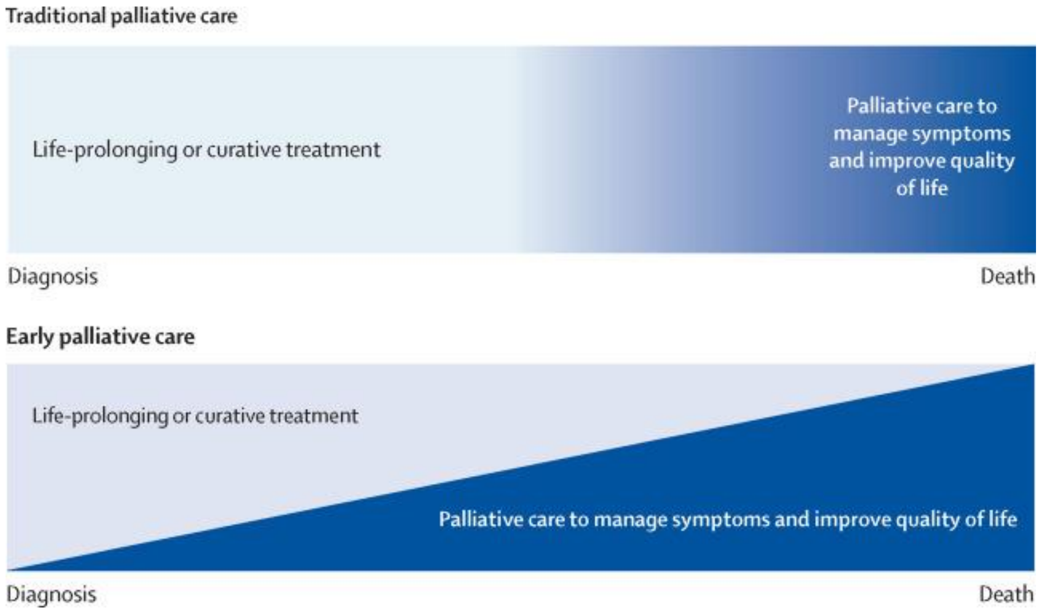

Figure 1. Traditional Palliative Care vs Early Palliative Care

Reprinted from The Lancet, Nov;19(11), Kaasa S, Loge JH, Aapro M, Albreht T, Anderson R, Bruera E, Brunelli C, Caraceni A, Cervantes A, Currow DC, Deliens L, Fallon M, Gómez-Batiste X, Grotmol KS, Hannon B, Haugen DF, Higginson IJ, Hjermstad MJ, Hui D, Jordan K, Kurita GP, Larkin PJ, Miccinesi G, Nauck F, Pribakovic R, Rodin G, Sjøgren P, Stone P, Zimmermann C, Lundeby T.,
Integration of oncology and palliative care: a Lancet Oncology Commission, e588-e653. (2018), with permission from Elsevier and Stein Kaasa" [14].

Early palliative care has shown to be beneficial. Temel et al published results from two randomised studies investigating early integration of palliative care to patients with NSCLC [13] and in the other study included patients with NSCLC, SCLC and gastro intestinal cancer [16]. They found that early palliative care had effect on survival and (QoL [13, 16]. A Danish research group, Johnsen et al, investigated the benefit of an early specialised palliative care intervention versus standard care, but did not find any significant improvements on symptoms and physco social problems [17].

Another Danish research group, Neergard et al, have newly published a study from 2020. They found that Advance Care Planning (ACP) as could be perceived as an early palliative care intervention offered to Danish patients with both malignant and non-malignant diseases improved survival significantly [18]. However, survival was primarily improved for patients with non-malignant disease [18]. An explanation may be that the patients with cancer already had access to palliative care and support [18], or it may have been a random finding. Despite recommendations that palliative care being provided as an integral part of oncology care it has been stated by several international organisations, for example: American Society of Clinical Oncology (ASCO), European Association for Palliative Care (EAPC) and European Partnership Against Cancer, that early palliative care is not implemented sufficient into oncology contexts [14, 19-21]. Kaasa et al, describes the main reason may be the tumor and treatment directed paradigm, that is in focus in oncology settings [14], and Prod'homme et al described that a barrier could be fear to initiate discussion of palliative care among health care professionals, while the patients still receive active treatment [22].

In a Danish study from 2013 published by The Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA) investigating general palliative care provided in hospital settings, it is described that almost half of all deaths (48%) in Denmark, occur at the hospitals [23]. Therefore the hospitals have an important role in providing palliative care [23]. Furthermore, 63% of the departments had a focus on palliative care and 49% of the departments had a focus on family caregivers needs [23]. It was also found that 14% of the hospitals ward managements had had allocated specific resources to improve health care professionals competences in providing palliative care [23]. The study concluded a need for improvement of palliative care provided in the hospital setting and a lack of research in palliative care provided at the general level [23]. Regard incurable cancer patients in Denmark, a study from 2013 also shows that 48-78% of patients had problems that were not met by health care professionals, such as pain, worries, fatigue, and problems regard work life and daily activities [24]. The Danish Health Authority states in the "Kræftpakke for Lungekræft (In English: Cancer Care Package for Lung Cancer) from 2018, that health care professionals must assess patients with palliative care needs and initiate interventions [11]. It is although not described in the recommendations, to what extent this should be done - and how [11]. In the Cancer Care Package for Mesothelioma (In Danish: Kræftpakke for Mesoteliom), from 2016 [11], palliative care is not mentioned, but rehabilitation is, although not specified. The two Cancer Care Packages however also refers to the Management Program for Rehabilitation and Palliative Care in Cancer patients (In Danish: Forløbsprogram for Rehabilitering og Palliation i forbindelse med kræft) in which it is stated that all patients with cancer must be assessed early in the course of disease with the Need assessment (In Danish: Behovsvurdering) by health care professionals working in hospital settings and afterwards systematically assessed during the course of treatment with regard to rehabilitation and palliative care needs [25]. However, an evaluation of the implementation of the Needs assessment (In Danish: Behovsvurdering) from 2017 showed that the implementation not yet has succeeded in all hospital settings [26]. Furthermore it was found that the Needs assessment (In Danish: Behovsvurdering) seemed suitable for assessing rehabilitation needs, but to a lesser degree the palliative care needs [26].

Expectations to palliative treatment and quality of life

Patients diagnosed with incurable thoracic cancer often have a short life expectancy and therefore it may be important early in the course of disease, to discuss future wishes for treatment and how they want to prioritise end-of-life [27]. (See the section "Conceptual Framework" on page 21 for definition of end-of-life). Every patient and family caregivers going into a course of palliative chemotherapy, have some considerations of the treatment they are going into. It however can be a challenge for patients and family caregivers to initiate and share these considerations, whilst research has shown that communication within the families about the disease is challenging, as they do not wish to hurt each other [28]. From international literature we know, that the patient and family may not have the same expectations of the treatment and may not discuss their expectations with each other or health care professionals, which can compromise optimal QoL and may make many patients live with a hope that the palliative intended treatment can cure the disease [29-31]. As treatment expectations have an impact on other decisions during treatment, it is important to discuss these expectations with patients and families [32]. Knowledge of patients' expectations derives primarily from international studies in the USA where a study from 2012 with 1193 patients including 710 patients with lung and colorectal cancer showed that 69% of the patients expected that palliative chemotherapy could cure them [30]. Another study from Germany with 384 lung cancer patients showed that 64% expected that palliative radiotherapy could cure them [33]. Furthermore, a study from Poland with 100 patients showed the same tendency, where 41% of patients with incurable lung cancer expected to be cured [31]. When talking about treatment expectations in palliative chemotherapy, there may be some age-related differences in treatment expectations, but it has been unexplored and likewise knowledge on the family caregivers treatment expectations is lacking. A focus on discussions of patients QoL during palliative chemotherapy is important, especially in the treatment decision making phase and after recurrence when discussing whether to continue or withdraw palliative treatment [15, 31]. International studies about QoL in patients with lung cancer receiving palliative chemotherapy, have reported that QoL was relatively stable during treatment [34-38]. However, there may also be some age-related differences in QoL during palliative chemotherapy. Only a small number of studies investigating age related differences in QoL were found [34, 39]. Winther et al and Hensing et al found no differences in QoL in patients aged <70 and ≥70 with lung cancer receiving palliative chemotherapy [34, 39]. Other studies have reported poor outcomes in QoL in elderly patients with lung cancer [40], however a study by Zimmerman et al reported in contrast a higher QoL in the younger patients diagnosed with incurable cancer [41]. There is a need to examine if age has an impact on QoL in Danish patients with incurable thoracic cancer.

Laws and guidelines regarding end-of-life decisions

In Denmark, as well in other countries end-of-life decisions are made on different levels. Laws and guidelines are developed to secure that patients with incurable disease live in accordance to their wishes and preferences near end-of-life [42]. The Danish and International laws and guidelines share many common subjects, for example patients right to participate in decisions, ethics, relief of symptoms, resuscitation, communication, euthanasia and assisted suicide and prolonging treatment [42]. However, one significant difference found in the laws between the European countries is the approach to euthanasia and assisted suicide, which is illegal in Denmark according to The Danish Criminal Law §237/ §240 [43], and in contrast legal in the Netherlands, Luxembourg and Belgium [42]. In Denmark, laws and guidelines ensures patients' rights regarding end-of-life. The Danish Health Care Act (In Danish: Sundhedsloven) states that all patients have a right to receive medical palliative care near end-of-life, for example pain medicine [44]. Patient Safety Authority (In Danish: Styrelsen for Patientsikkerhed) recently published a clinical guideline on how and when to use palliative sedation [45]. Danish Patient Safety Authority has with a legally binding treatment will (In Danish: Behandlingstestamente) made it possible for patients with an incurable cancer to reject life prolonging treatment. Furthermore, it is possible to ensure that families could decide on the level of treatment if the patient become incapacitated [46].

The Danish Government presents in "Cancer Plan IV", 16 initiatives regarding the future work with cancer in Denmark [47]. One of the initiatives is that palliative care in Denmark needs improvement [47]. From this initiative, The Danish Health Authority have published the Recommendations for Palliative Care in Denmark (In Danish: Anbefalinger for den palliative indsats i Denmark), and hereby they state that patients with incurable illness and their families should be offered formal end-of-life discussions to discuss wishes for end-of-life [15]. It means that health care professionals must involve and invite both patients and families to attend end-of-life discussions during palliative chemotherapy with the aim to discuss the patients and families wishes for end-of-life. However, In Denmark there are not any systematic methods to talk to patients and their family caregivers about end-of-life, and to improve current practice and find opportunities for development, there is a need to gain knowledge on how end-of-life discussions currently are carried out.

End-of-life discussions in oncology

End-of-life discussions with patients and family caregivers, as also can be considered as an early palliative care intervention, are important throughout the course of illness when planning future treatment or other wishes related to end-of-life [48].

International studies have concluded benefits in end-of-life discussions with patients diagnosed with incurable cancer and they are furthermore associated with less aggressive treatment near end-of-life, treatment in line with patients' wishes, earlier hospice referral, decreased hospitalisation, and higher QoL [29, 49, 50]. Studies have also shown that patients with cancer and their families wish to actively take part in planning end-of-life care [51-53]. Family caregivers are an important part in the course of disease, and they should have knowledge of the patient's wishes, if the patient become incapable to make own decisions. End-of-life discussions are in the literature often used in relation to and described as a

discussion between a patient, family caregiver and a physician. These studies with focus on patient, family and physician relationship describes that end-of-life discussions often occur too late in the trajectory [29, 54, 55]. A study by Wright et al., found that 60% of patients with incurable cancer did not have these discussions with their physician at all [29]. Mack et al found that only 27% of physician treating patients with incurable lung and colorectal cancer had end-of-life discussions [55].
Oncology nurses, as well as others health care professionals have an important role in integrating palliative care into the oncology treatment, and are essential in providing disease and symptom management, psychosocial and spiritual support, and in encouraging discussions about end-of-life [56]. Nurses often spend a lot of time with patients and family caregivers and thereby have an opportunity to facilitate discussions in a timely manner [57]. Internationally, there is little knowledge of the nurses' involvement in end-of-life discussions in an oncology setting [58]. A Swedish study from Rylander et al found that nurses have an important role in the communication with patients in the course of oncology treatment, but also concluded that end-of-life discussions were mainly medical oriented [59]. International reviews have focused on advance care planning (ACP) conversation in acute care and home care settings and treatment decision making [60-62]. The studies found that the nurses were involved in different degrees in decision making [62], the nurses lacked knowledge, training and time to be involved in such conversations [60, 61]. In Denmark, the research about end-of-life discussions is also sparse. A newly published Danish study by Bergenholtz et al., investigated a mixed population of patients and families end-of-life discussions in an acute hospital setting, and found that the wish to talk about end-of-life issues was an individual matter, some patients and spouses wanted to talk about end-of-life while other do not wish to have conversations [63]. Bergenholtz et al. have also investigated the perspective of health care professionals in Denmark and found that there are many challenging factors talking about end-of-life in an acute hospital setting, here among: the setting, unclear roles, lack of competences among the nurses [64]. However, there is still a total lack of studies investigating incurable thoracic cancer patients', family caregivers, and nurses' perspectives of end-of-life discussions.

In summary, incurable patients with NSCLC, SCLC and mesothelioma (thoracic cancer) have a severe prognosis and within a short timeframe they need to make some important decisions regarding how they want to prioritise end-of-life. International research have shown that a high percentage of patients with incurable cancer have expectations to be cured from the palliative treatment [30, 31]. Studies examining whether age has an impact on treatment expectations remain unexplored, and there is a lack of studies focusing on Danish patients' and family caregivers' treatment expectations. A few studies have shown that patients have a stable QoL during palliative treatment [34-38], but there is a lack of knowledge if age has an impact on QoL. This knowledge is valuable when making treatment decisions for patients with thoracic cancer, and also for health care professionals in end-of-life discussions. End-of-life discussions have shown to be beneficial and are often described as a conversation between a physician and a patient, where discussion is not initiated or initiated too late [29, 54, 55]. However, nurses spend a lot of time with the patients and family caregivers and have an opportunity to initiate, facilitate or follow-up end-of-life discussions in a timely manner, however there is a lack of studies investigating both patients, family caregivers and nurses involvement in these discussions. In this PhD study the nurses' perspective were chosen, acknowledging that the physician are an important aspect of in end-of-life discussions. This led to the following section where aim and research questions are presented.

Aim and research questions

The overall aim of this PhD study was to gain knowledge about expectations, QoL and end-of-life discussions in patients diagnosed with incurable thoracic cancer during their course with palliative chemotherapy. The PhD study included the perspective of both patients, family caregivers and nurses. The research questions that guided the study are presented below:

- Study 1:
  What are the differences in treatment expectations and QoL among patients with thoracic cancer aged <70 and ≥70 years who are receiving palliative chemotherapy and what are family caregivers' expectations for palliative chemotherapy?

- Study 2:
  What are nurses' perspectives on their involvement in end-of-life discussions - including barriers and facilitators - with patients with incurable cancer and their family caregivers?

- Study 3:
  What is the current practice for end-of-life discussions with incurable lung cancer patients and their family caregivers in an outpatient oncology clinic from the perspectives of patients, family caregivers, and nurses?

Conceptual framework

In this section follows an examination of the overall conceptual framework that guided this PhD study, following definitions of important concepts: *Palliative care, System theory, Quality of life, End-of-life, End-of-life discussions, Nurses, and Family caregivers.*

Palliative care

The palliative care movement was established by the English doctor, nurse and social worker Dame Cicely Saunders (Saunders) (1918-2005) [65] and originated from the Hospice philosophy. In 1967, Saunders established the first Hospice (St. Christopher) and by that introduced the concept "total pain", which described pain to be physical, emotional, social and spiritual [66]. The focus at St. Christopher's Hospice in London was on QoL, versus the length of life, where in contrast, before the establishment of the concept, pain was treated in the patients' home or on busy hospital wards. Subsequently the Hospice movement expanded all over the world [66], and in 1979 it was stated that good care as provided in Hospices should be spread out to other settings [67]. In Denmark this led to the first Hospice established in 1992 in Hellerup and since then the specialised palliative care has further developed. According to REHPA in 2021, there are 54 specialised palliative care units in Denmark, including hospices, palliative care teams and palliative care wards [68].

In Denmark the development of palliative care has been through changes and these have been investigated by Mette Raunkiær (M.R.) through reports of health politics from 1985-2001 [69]. Death in Denmark has been historically associated with cancer and not with other chronic diseases, and palliative care has been offered primarily to patients with cancer [69], which is still the case according to a recent report of the National Audit (In Danish: Rigsrevisionen) from 2021 [70]. According M.R. a possible explanation may be that it have been easier to mark the transition from curative to palliative care in cancer patients [69]. From 2017 and until now, work is being done to expand the palliative care to patients with all kinds of life threatening diseases [15], and the next step may be that it is expanded to all patients with severe illness [71]. See reflections in next section.

In most countries palliative care is organised into two levels: Specialised and general palliative care [15, 72, 73]: Specialised palliative care is defined as a care provided of health care professionals who have provision of palliative care as their main activity [15, 72]. The care is provided by for example hospices, palliative care teams, or specialised palliative care units at hospitals. General palliative care is defined as care provided to those affected by life-threatening diseases as a part of standard practice by healthcare professional not part of a specialised palliative care team, for example the nurses and physicians at the outpatient oncology clinic at Odense University Hospital. The general level is obligated to implement initiatives that supports the needs of the entire family from the time of diagnosis, however palliative care is not their main task [15, 72]. The target group for referral to specialised palliative care in Denmark are: "*persons with palliative needs of high complexity…*" [15], this however can be difficult for the individual health care professionals when a person has complex needs and this may be the reason why a newly report published by the National Audit (In Danish: Rigsrevisionen) in 2020 have concluded that not all patients in Denmark with need for specialised palliative care are referred [70].

Denmark follows the WHO definition of palliative care from 2002. The definition also take its starting point from Saunders concept of "total pain", and seeks to embrace all four dimensions of pain: *"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [74].* In Denmark, the latest recommendations from 2017, have translated "palliative approach" (in Danish: tilgang) to "palliative effort" (in Danish: indsats) [15]. The concept "effort" may be understood as an action, in contrast to "approach" which in a higher degree refers to a more relational and embracing approach, that may imply a meeting and to be seen. This may affect the way palliative care is practiced and if it is so, it is problematic.

The WHO definition of palliative care – is continuously being discussed, and the palliative care definition is challenged by palliative care specialists all over the world. In the end of 2020, a new definition of palliative care was released from the International Association for Hospice and Palliative Care [71]. The new definition: *"Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers"* [71]. The new definition focus is on relief of suffering for patients rather than focusing on life threatening illness as described in the current WHO definition [71]. In the context of this PhD study, it can be discussed whether the definition from 2020 [71] is too broad. The definition however may be suitable to extend the palliative care into other context, for example in nursing homes, where patients live longer with chronic diseases and the new definition also include children. I am although aware that research is continually under improvement regarding new treatment modalities. When anticancer treatment in the future can control incurable thoracic cancer and stop it from the rapid progress that they current experiencing the new palliative care definition from 2020, may be suitable for this patient group as well.

Although, in the light of this considerations, I have chosen that this PhD study, builds on the WHO's definition of palliative care from 2002 were palliative care is provided to those with life-threatening illness [74].

System theory

System theory has been the overall frame in this PhD study, acknowledging that the whole family is important and should be included in a course with incurable disease [75]. Historically the general system theory has its origin from the biologist Ludwig von Bertalanffy (1901-1972) (Bertalanffy) [76]. Bertalanffy argued in his book "General System Theory", that systems are everywhere and one must understand the parts and the interrelationships, in order to understand the whole [77]. The general system theory has been used across several disciplines and is used in a wide range relation to for instance organisations, families etc. [76]. In the family system theory, developed from the general system theory, the aim is to discover patterns and behaviours in family relations [76]. The family system theory are defined as an organised collection of sub-systems that are working together as a complex unit [75]. The patients are not just individuals, but are a part of a larger system, a family unit, that affects each other [76]. For example, when a family member become ill, it will affect all individually in different ways. The theory also describes, that the family are arranged in a hierarchy, and are organised in smaller sub-systems, such as spouse, parents and also siblings, but they all interacts within a larger system in the society [76], for example the health care system. In summary, there are ongoing interactions between patient, family caregivers and health care professionals when patients are going into a course of palliative chemotherapy, and it is my belief that illness is a family affair, and all parties should be involved. Understanding of families as a system are important in end-of-life discussions.

Quality of life

QoL is by the World Health Organisation (WHO) defined as: *"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."* [78]. QoL is quantified measurements of individuals' subjective well-being [79]. In the 1960s, the first QoL studies were published within the field of medicine [80]. From then, the concept of QoL, has gained more and more attention in the literature, and it has been acknowledged as an important way to asses any benefit of treatment [79]. There exist many different tools to asses patients QoL, some generic and others disease specific, but in common they are subjective, multidimensional and encompasses many aspects of individuals' well-being [79], for instance the physical, social/family, emotional, and functional well-being.

End-of-life

Internationally, there is no consensus of the concept end-of-life [72, 81]. A systematic review by Hui et al from 2014 reviewed the concept "end-of-life" and found that end-of-life is defined in a wide range. Some defined end-of-life from a period lasting 1-2 years, and other have defined end-of-life only to last

48-72 hours [81]. In a Danish clinical context, end-of-life have from 2011-2017 been divided into three phases describing the severity of the disease [82, 83]. These three phases are however not a part of the newest recommendations for palliative care in Denmark published in 2017 [15]. There are no explicit reasons for why the three phases cannot form a part of the newest palliative care recommendations from 2017, but the phases were developed from a haematological study published by Dalgaard et al [82] and this could be the main reason why they are not mentioned in the recommendations from 2017. However, clinicians working at the outpatient oncology clinic where this PhD study took place, still uses, and refers to the phases when talking about patients with incurable cancer. For clinicians, it still makes sense to use the three phases, because the phases give a quick overview with regard to the patients' course of disease and makes it easier for clinicians to initiate relevant interventions targeted to each phase. To give an overview where the patients in this PhD study are in the course of disease, I have chosen that this PhD study will follow the three phases: The first phase "early palliative care", where the patients are offered life prolonging treatment. Expected remaining lifetime is a few years. The second phase "late palliative phase", where life prolonging treatment is often not relevant or possible anymore. Expected remaining lifetime is often months. The third phase "The terminal phase", where the patient is dying. Expected remaining life time is days to weeks [83]. Patients included in this PhD study, receives life prolonging palliative chemotherapy, and can be considered to be in the "early palliative phase" with the remaining lifetime expected to be around 1-2 years as described by Dalgaard and in the palliative care recommendations from 2011 [82, 83].

End-of-life discussions

Internationally, many different terms are used when talking about end-of-life matters for example: end-of-life discussions, end-of-life communication, end-of-life conversation, and end-of-life care discussions [48, 64, 84]. These definitions are used as a broad concept to involve patients and families to talk about end-of-life matters.

A more systematic approach to talking to patients and families about end-of-life matters are among others Advance Care Planning (ACP)[85], also mentioned by the palliative care recommendations from 2017 [83]. ACP is an overall approach defined as: *"a process whereby a patient, in consultation with health care providers, family members, and important others, makes decisions about his or her future health care*" [85]. In contrast to Denmark, the USA have used ACP for many decades and it was introduced on the 1970's but primarily as a legal document target to the general public [86]. Now ACP have developed and are now used more as a model of communication [86, 87]. Internationally ACP are recommended as an integral part of oncology practice, but not implemented as best practice yet [85]. A systematic review from 2018 concluded that oncologists didn't want to take away hope, and hesitated in initiating ACP conversations. Furthermore, recommendations of how ACP should be implemented lacked [85]. The systematic review also concluded that most ACP conversation was mainly completed by oncologist, but they also recommend that ACP could be performed by the nurses [85]. In, Denmark ACP is a relatively new approach, and work is being done to implement ACP, mainly at the specialised palliative care level [88]. The Danish Society for Lung Medicine (In Danish: Dansk Selskab for Lungemedicinsk Arbejdsgruppe) have also published recommendations for what they call: “Fælles planlægning af behandlingsmål” (In English: ACP) and recommend that “Fælles planlægning af behandlingsmål” should be implemented as a part of the specialist training in lung medicine [89]. However, as described before ACP are not fully implemented in Denmark [88].

Another systematic approach in Denmark is Shared Decision Making (SDM)[90]. SDM is an approach where patients and health care professionals work together to decide and discuss a future treatment [91]. SDM can be seen as a composition to the paternalistic approach where the physician decide which treatment suits best [92], and the concept was introduced into medicine in the 1980’s where patients became more involved in treatment decisions. However, Internationally SDM in patients with incurable cancer are not implemented in daily practice, and in the literature, it is described that one main challenge is that it is still taboo to talk about death [90]. In Denmark a Center for Shared Decision Making was established in 2014 at Sygehus Lillebælt [93], but SDM is at an early stage in Denmark and not fully implemented in clinical practice [94].

A more legal document used internationally is called “advance directive” and specify what treatment the patients wish if he/she become incapable of making their own decisions. This directive can be a part of the ACP conversations. Some are made by the patient and family caregivers, others made by lawyers or organisations [95]. Noticeably all countries have their own laws and requirements regarding an advance directive. An example of an advance directive is Living Wills [95]. However, there are many different types of advance directives [95]. In Denmark, similar documents are not used in daily practice. However, a legal and similar document is an advance directive the “Behandlingstestamente” (In English: Treatment will) as mentioned in the background section. This is an advance directive were patients can write their wishes, example life prolonging treatment [46]. Acknowledging that many concepts exist with different definitions, I have been inspired by the existing approaches and definitions, chosen to use the concept end-of-life discussions in this thesis, defined as a broad and informal approach for talking with patients and family caregivers about end-of-life: *“End-of-life discussion is a discussion between a patient, family caregiver and a nurse, it can be both related to treatment, prognosis but can also cover preferences and wishes for daily life”* [63, 64].

Nurses

In study 2, both oncology and haematology nurses were included and when introducing study 2 in this thesis, they will be referred to simply as nurses.

In study 3, only oncology nurses were included but they will also be referred to as nurses.

Both haematological and oncological nurses are responsible for administering chemotherapy and talking to patients with incurable cancer and their families about end-of-life issues. All nurses responsible for chemotherapy have completed a course of giving chemotherapy, including themes as for example: pharmacology, side effects, immunotherapy, ethical and legal aspects, care and information to patients, but they do not receive any formal training in end-of-life discussions [96].

Family caregivers

Due to the multiple existing family constellations and synonyms to the concept family it is important to clarify what family caregivers mean through this PhD study. In the literature several synonyms to "family" are used. Among others, family caregivers (as used throughout this PhD study), family members, next of kin and relatives. According to Janice Bell, a nurse and researcher that has focused on families within the context of nursing, states that *"our ideas about family influence how we behave",* [97] and of course it is essential to reflect on as a nurse and a researcher, what is family? Janice Bell came up with her favourite definition, which I thought was quite interesting: *"Those people who give a damn about you"* [97]. When reflecting I found this definition quite correct. However, in this PhD study family caregivers are defined in a broad context and the family are chosen by the patient. This also means that family caregivers in this PhD study can be both blood-related and/or close friends [98]. This definition is chosen as I believe it is solely the patient who shall and can decide who is important to them.

Methods and results

When this PhD study was initiated, it aimed to include patients with thoracic- and pancreatic cancer, their family caregivers, nurses, and oncologists. Unfortunately, it did not went as planned, due to different reasons, the main one being the first wave of covid-19, as researchers and PhD students were suddenly not allowed to enter the oncology outpatient clinic. Furthermore, the oncologists did not wish to be a part of the study, and we therefore had to change the study protocol. This was a challenge, and it also gave some considerations that will be discussed further in the section "Methodological considerations". The former study 1 was planned to include patients with thoracic-/pancreatic cancer and their families. The former study 2 was planned to be a study using participant observations and interviews including patients with thoracic-/pancreatic cancer and their families and the former study 3 was planned to be a study using participant observations and interviews including nurses and oncologists.

In the current PhD study, the overall aim was to gain knowledge on expectations, QoL and end-of-life discussions in patients diagnosed with incurable thoracic cancer during their course with palliative chemotherapy cancer. To provide answers to the above-mentioned research questions, three different methodologies were combined: a longitudinal prospective survey study, a systematic integrative review and participant observations and interviews. When structuring the "Methods and results" section I have been inspired by Carter and Littles "model of thinking" [99]. They argue that epistemology, methodology and method are three factors that are essential to reflect upon to underpin research, as they all affect each other. An overview of the three studies in relation to epistemology, methodology, methods, and results are presented in **Table 1**. Carter and Little states that epistemology affects the relationship between the participant and researcher [99]. The methodology, is described by a theory of how the research should be carried out, and finally method; the way the researcher conducts the study, also described as the researchers' actions [99]. In the following section I will present the setting for study 1 and 3, following an elaboration on the epistemological approach of the three studies. Next a presentation of the methodology, methods and results will be carried out for the three studies.

	Study 1 **A longitudinal prospective study**	**Study 2** **A systematic integrative review**	**Study 3** **A phenomenological hermeneutic study**
Epistemology	Positivist	Phenomenological/hermeneutic	Phenomenological/hermeneutic
Methodology	FACT-G survey Treatment expectations survey	A systematic integrative review	Participant observations Informal interviews Individual interviews Joint interviews Focusgroup interviews
Methods	Redcap Stata Descriptive statistics Wilcoxon rank test Fishers exact test Students t-test ANOVA Cohens Kappa	Covidence Whittemore and Knafls approach integrative review and to analysis	Nvivo Analysis inspired by a Paul Ricoeur approach
Results	48 patients with thoracic cancer 36 family caregivers No significant differences in treatment expectations between age groups. 28% of patients in the younger group expected a cure at the first cycle, compared to 7% in the older group. Among family caregivers, n=13 (36%) expected a cure. No statistically significant difference was observed for the interaction term of QoL and time	15 peer reviewed articles 12 qualitative articles 3 quantitative articles Four themes were identified as related to nurses' roles, barriers, and facilitators in end-of-life discussions: • *Nursing roles* • *Trust building* • *Nurse competence* • *Medical issues*	28 participants included 9 patients with thoracic cancer 8 family caregivers 11 oncology nurses The analysis identified three themes: • *Timing of end-of-life discussion* • *Content in end-of-life discussion* • *Challenges in end-of-life discussions*

Table 1. Overview of the three studies

Setting

In study 1 and study 3, all data was collected in the outpatient oncology clinic which treats patients with mainly thoracic cancer. The outpatient oncology clinic can be considered to be divided into three smaller sections: *The information clinic, the chemotherapy clinic* and *the follow up clinic.* See **Figure 3** for simplified course of treatment. In daily practice, the sections overlap with staff, rooms, and time. At the information clinic, an oncologist and a nurse are responsible for the daily program. This is often patient and family caregivers first contact with the outpatient oncology clinic. Here it is decided which palliative chemotherapy should be offered and if it should be offered. The chemotherapy clinic is run by nurses who provide the chemotherapy. Patients typically receive palliative chemotherapy every third week. In the follow up clinic, oncologists and nurses reviews the patients who have already undergone treatment with CT scans to see if the cancer has responded to the treatment. When scan results show that there is no longer an effect from the current treatment, which means that the cancer has grown and thereby progressed further, second line treatment is the next option, if the performance status allows it [9], and so forth. After second line treatment, it is possible to initiate both 3rd, 4th and even 5th line. Unfortunately, there is sparse evidence about the effect and value of the new treatment, which leaves a responsibility to the patients, family caregivers and oncologist to decide whether to initiate new treatment regimens or not based on previous experience with the treatment, side-effects and tumour response [100].

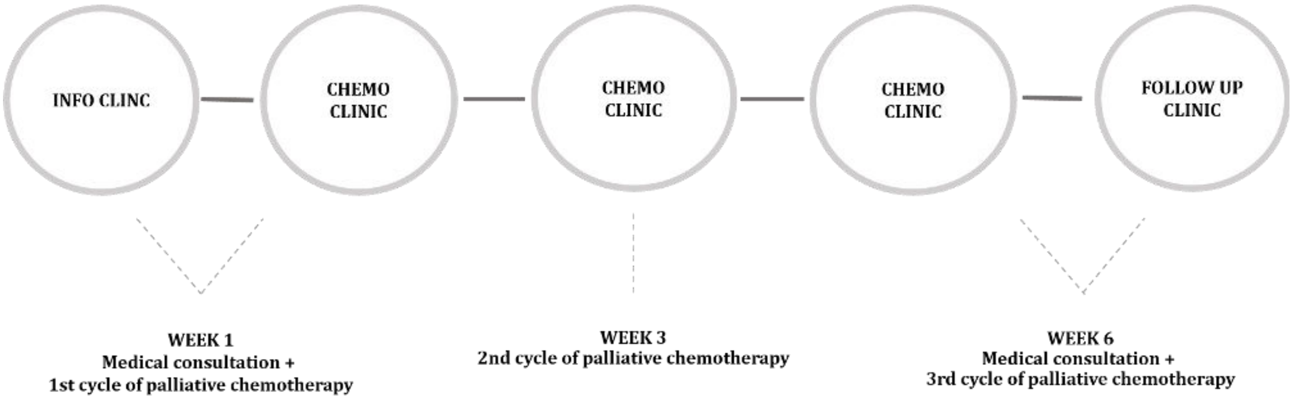

Figure 3. Overview over the course of treatment

Epistemology

The above-mentioned research questions refer to two different philosophies: the positivist (study 1) and phenomenological hermeneutic (study 2 and study 3).

Study 1 are conducted within philosophy of positivism. The founder of the classic positivism was the French engineer and philosopher August Comte (Comte) (1798 - 1857) [101, 102]. Comte claimed that only concrete knowledge for instance static data gained through scientific method, can be considered as truthful [101, 102]. A researcher within philosophy of positivism must be separated from the research [101, 102], and in study 1, I have had minimal influence of the creation of data. However, I planned the study, developed the research question and a question regarding treatment expectations, I chose the FACT-G survey and handed out the surveys to the patients and families. Even though patients and families answered the survey without my interference, this together may have affected the data. Study 1 is placed within the philosophies of positivism, but I believe it is difficult to be total separated from the research, as argued by Comte [101, 102]. My choice throughout the study and my appearance when handing out the survey to patients and families may potential have affected the data. In study 2 and 3, I have been involved in and affected the entire research process, with my presence and my questions. The philosophical underpinnings in the qualitative studies, study 2 and study 3, are inspired by a phenomenological hermeneutical approach, and especially by Paul Riceours (Ricoeur) thinking. The founder of phenomenology was the German philosopher Edmund Husserl (Husserl)(1859-1938) [103]. The overall aim of phenomenology is to understand the first person's experiences in relation to the phenomena in focus, which in study 2 and study 3 were end-of-life discussions. In relation to study 2, the reading of full articles before analysing data were initially inspired by the phenomenology approach were I openly approached data and coded descriptively. However, I was aware that my preconceptions could impact the process. Before initiating the study in 2017, I wrote down my preconceptions and considerations of embarking upon this PhD. See **Appendix 1**. This was important to me, because I wanted to secure that my preconceptions were not just verified in the PhD study. I continually reflected on my preconception and together with the analysis, methods and theories it helped me to ensure that my analysis and interpretation was not a repetition of my own preconceptions but driven by the data. Husserl worked with bracketing preconceptions in order to make pure descriptions of the phenomena [103]. Phenomenology was further developed of among others Husserl, Heidegger, Gadamer and Ricoeur, and especially Gadamer and Ricoeur developed phenomenology to take a more interpretive approach to gain and deepen insight into perspectives of the individuals, as he, just as Ricoeur didn't believe it was possible to make pure descriptions [104, 105]. Both Gadamer and Ricoeur stated that it is impossible to experience new things with a total open mind. Gadamer and Ricoeur claimed that preconceptions should be used actively to interpret and gain a new understanding of the phenomena in focus [105]. In study 3, observations and interviews, were inspired and guided by the open phenomenological approach. For example, I approached the observations and interviews with an open mind with the purpose to investigate patients, families and nurses experiences during palliative chemotherapy, acknowledging that they were the experts and had to learn me about what it was like to be involved in end-of-life discussions. Just as described, I actively used my preconceptions. An example was in study 3, when one of my preconceptions was verified during the data analysis (that end-of-life discussions was often not carried out in practice), I once again read data and ensured that this was a finding from the analysis and not solely my preconception of what I believed I would find. Finally, the hermeneutics guided study 2 and 3, as described by Gadamer. Gadamer presented the hermeneutical circle as a tool to gain and expand knowledge [105]. Hermeneutics also means "interpretation of texts", and in study 2 and study 3 the approach of hermeneutics was especially useful when analysing and interpreting data. Analysing and interpretation is a dynamic process, an example is that I in study 3 continuously went back and forward to the observations and interviews - the patients' perspective, the family caregivers perspectives and the nurses perspectives, until I reached a new understanding of the whole meaning, and from this could draw some similarities across the data. The three studies were conducted within different philosophies. However, in combination the knowledge provided can give a more nuanced picture, compared to if the studies were only conducted within one philosophy [106].

Study 1: A longitudinal prospective study

Aim

The study aim was to examine differences in treatment expectations and QoL among patients with thoracic cancer aged <70 and ≥70 years who were receiving palliative chemotherapy and to assess family caregivers' expectations for palliative chemotherapy. We hypothesised that patients aged ≥70 years would have worse QoL and lower treatment expectations than younger patients.

Research question

What are the differences in treatment expectations and QoL among patients with thoracic cancer aged <70 and ≥70 years who are receiving palliative chemotherapy and what are family caregivers' expectations for palliative chemotherapy?

Methodology

This study was designed as a longitudinal prospective survey study, measuring patients' treatment expectations and QoL and family caregivers' treatment expectations because knowledge of changes in QoL and treatment expectations lacked in Danish patients with thoracic cancer. Furthermore, it would provide important knowledge that may be beneficial in end-of-life discussions with patients and families.

The survey for the patients contained a one side questionnaire containing socio-demographic data, at their first treatment regarding co-habitation, level of education, job situation, and children, following a question on treatment expectations and QoL. The survey to family caregivers also contained sociodemographic information such as age, and education following a question of treatment expectations.

Question - Treatment expectations

There is increasing research in expectations regarding medical treatment [107]. However, there is no common understanding of the concept. In study 1 in this PhD study, we investigated patients and family caregivers expectations, the concept "expectations" are used to asses patients expectations of palliative chemotherapy and in this context expectations are defined as: *"An expectation is a belief of what may happen in the future"* [108].

As there existed no validated questionnaire to access treatment expectations of patients and families, a new question with an inspiration from earlier studies investigating treatment expectations were developed. By a thorough literature search of the databases PubMed and CINAHL, in august 2017, with help from an experienced Liberian we identified studies investigating patients with thoracic cancers treatment expectations. We also searched through relevant webpages, such as The Danish Cancer Society and The Danish National Board of Health. We identified two articles assessing patients' perspectives on palliative chemotherapy: Mende et al from 2013 and Mack et al from 2015 [32, 109]. Mende et al investigated patients' perspectives of survival to palliative chemotherapy to colorectal cancer [32], and Mack et al investigated colorectal and lung cancer patients' expectations to palliative chemotherapy and asked patients to state the expected survival in months [109]. Mack et al asked patients: "*After talking with your doctors about chemotherapy, how likely did you think it was that chemotherapy would cure your cancer?"*. The patients could answer: *"very likely," "somewhat likely," "a little likely," "not at all likely," and "don't know"* [109].

With inspiration from these current studies, we developed a question that was adjusted to fit both patients and family caregivers. The question was pilot tested with in a total n=10 patients and n=10 family caregivers. We also performed in total n=20 cognitive interviews with patients diagnosed thoracic cancer and their family caregivers. Pilot testing was initiated and carried out following inspiration from the work by Drennan and Knafl [110, 111]. The patients and family caregivers assessed both appearance of the entire survey, the understanding of questions and they also assessed the word in the questions. Overall, patients and family caregivers were satisfied after pilot testing and the questions were only adjusted with some small corrections of the overall appearance of the survey. See **Figure 3,** for the final version of the question regarding treatment expectations.

Efter du har snakket med din læge om kræftbehandlingen, hvilke er dine primære forventninger til den behandling du skal have i dag? *(Sæt gerne flere krydser)*	
Lindring af ubehag eller smerter ☐	**Vinde levetid** ☐
Helbredelse ☐	**Ved ikke** ☐

Figure 3. Final version of questions regarding treatment expectations

Questionnaire - The Functional Assessment of Cancer Therapy (FACT-G)

Before initiating the study we discussed the two most used questionnaires for assessing patients QoL among patients with cancer: The European Organization for Research and Treatment of Cancer QoL-30 (EORTC QoL-30) [112] and The Functional Assessment of Cancer Therapy - General questionnaire (FACT-G) [113].

We chose the FACT-G which is an instrument that uses self-reports to assess QoL for patients with cancer – in cancer treatment, because it contained questions that fitted the overall frame of this PhD, in which families were important, for instance a question in this survey was: "*I get support from family and friends*". It was also possible to choose the "FACT-LUNG" questionnaire, but as we before study start wanted to include patients with pancreatic cancer and compare those two groups, the general FACT scheme was chosen to this study. Unfortunately, due to Covid-19, we had to exclude patients with pancreatic cancer and initiated an integrative review instead. The FACT-G is a reliable and validated oncology specific QoL instrument [114]. The 28 questions are covering four domains: physical well-being social/family well-being, emotional well-being, and functional well-being. Higher scores suggest better QoL [113]. The FACT-G questionnaire was scored in accordance with the FACT administration and scoring guidelines [113]. FACT-G generates an overall score and four sub-scale scores and uses a 5-point rating scale (0 = Not at all; 1 = A little bit; 2 = somewhat; 3 = Quite a bit; and 4 = Very much). The FACT-G total score is calculated as the sum of the four subscale scores, provided the overall item response if more than 80% of the questions are answered in the total FACT-G [115]. Negatively worded questions are reverse scored prior to summing so that higher sub-scale and total scores indicate better QoL [115].

Methods

This longitudinal prospective survey study included both patients and family caregivers. Patients and family caregivers were recruited from the outpatient clinic at the Department of Oncology at Odense University Hospital from December 2017 – September 2019.

Participants and data collection

Patients diagnosed with incurable thoracic cancer (non-small-cell lung cancer, NSCLC, small-cell lung cancer, SCLC, and mesothelioma) and were about to start 1st line palliative chemotherapy were included. The family caregiver who accompanied the patient was also included if the patient consented. Patients were screened in the booking system "Mosaiq Schedule", by the PhD student and a research nurse in the inclusion period. In "Mosaiq Schedule", it was possible to find a schedule of patients' course of treatment including dates and time for the next appointment in the outpatient oncology clinic. Patients completed the paper-based survey three times; prior to their first, second and third cycle of palliative chemotherapy, and the family caregivers once, prior to the first cycle of palliative chemotherapy. See **Figure 4** below for an overview of data collection. See **Appendix 2** for participant information to patients – study 1 and **Appendix 3** for participant information to family caregivers – study 1. See **Appendix 4** for survey handed out to patients, and **Appendix 5** for survey handed out to family caregivers. Additional data from the patients' medical record was included: diagnosis, TNM, Performance status at baseline, current performance status, former type of chemotherapy, current type of chemotherapy, current line of chemotherapy, treatment break, hospitalisation, if the patients were followed by a palliative care team.

Patients and their family caregivers were in a very vulnerable situation and were experiencing a very stressful time due to their diagnosis and they were trying to cope. It was complicated and time consuming to include the patients and their family caregivers. When we first met the patients and their family caregivers at the chemotherapy clinic they were told about the study, but what was most important to them was to talk to someone about their disease progression. Often it took up to one hour talking to the patient and their families, when they told their story and they often cried. Consequently, patients and families were willing to participate and found the project very important and wanted to help. It was necessary to follow the patients planned visits day to day, to see if a visit was cancelled or postponed. The patients often experienced side effects from treatment, had abnormal blood sample, bad general health and often their treatment was postponed. Furthermore, all patients received a text message the day before they had an appointment in the oncology outpatient clinic and some patients requested a phone call before their appointment to remind them to bring the survey with them to the appointment. (See further ethical reflections in the section "Ethical considerations" on page 54). That also meant that T.I. text messaged/called every single patient up to three times during the study course and met every single patient up to three times to receive their surveys. When planning this study, we had hoped for the oncologist' participation, regarding answer some question in relation to both study 1 and study 3. As described earlier, they did not wish to be a part of the study.

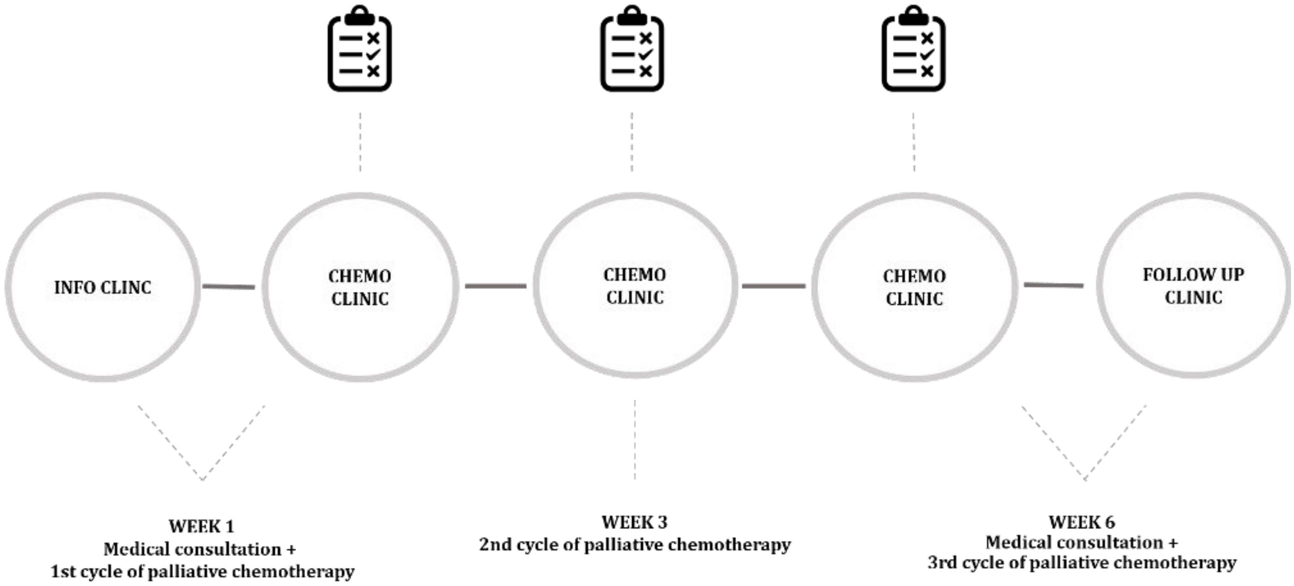

Figure 4. Illustration of data collection regarding the survey
The survey icon symbolises the time the patients filled out the question of treatment expectations and QoL. The family caregiver only answered in week 1.

Data management

All survey data were collected and managed using Research Electronic Data Capture (REDCap) tools hosted at Open Patient data Explorative Network (OPEN) [116, 117].

Statistical analysis

Using the Wilcoxon rank sum test and Fisher's exact test the statistical significance of differences between patient age groups was assessed. The statistical significance of changes in patients' treatment expectations from baseline to the second and third cycles of chemotherapy was assessed with Student's t-test. The Cohen's kappa coefficient assessed agreement between patients' and family caregivers' treatment expectations, ranging from a value of 0 indicating non-agreement and a value of 1 indicating perfect agreement [26]. Missing items in sub-scales were handled according to the FACIT Administration and Scoring Guidelines [27]. The changes over time from baseline in total and domain FACT-G scores were evaluated with one-way ANOVA with the Greenhouse-Geisser correction and a QoL and time interaction term. Moreover, repeated measures one-way ANOVA were also used for sub analyses of FACT-G domains. Changes of ≥ 5 points in FACT-G total scores and ≥ 2 points in domain scores were considered clinically meaningful [118]. A p value < .05 was considered statistically significant. All analyses were conducted using STATA 15 [28].

Results

The full results of this study are presented in paper 1 [119]. The results section includes a summary of the main results.

In total n=31 males and n=17 females, median age 66 (range 49-81) diagnosed incurable thoracic cancer starting a new line of palliative chemotherapy (1st line or above). N=31 were diagnosed with NSCLC, n=8 with SCLC and n=9 with mesothelioma. We also included n=36 of their family caregivers, median age 62.5 (range 19-74). See **Paper 1**, **Table 2** and **Table 2** for patient and family caregivers for a short overview of characteristics.

Treatment expectations

In the results regarding treatment expectations, there was no significant difference in treatment expectations among the two age groups. 28% of patients in the age group <70 years expected a cure at the first cycle and in the age group ≥70 years 7% expected a cure. However, this was not statistical significante ($p = 0.1$). In the group with the family caregivers, n=13 (36%) expected a cure. Of family caregivers who expected a cure, n=12 (92%) provided care for patients <70 years. See **Figure 5** for overview of results of treatment expectations.

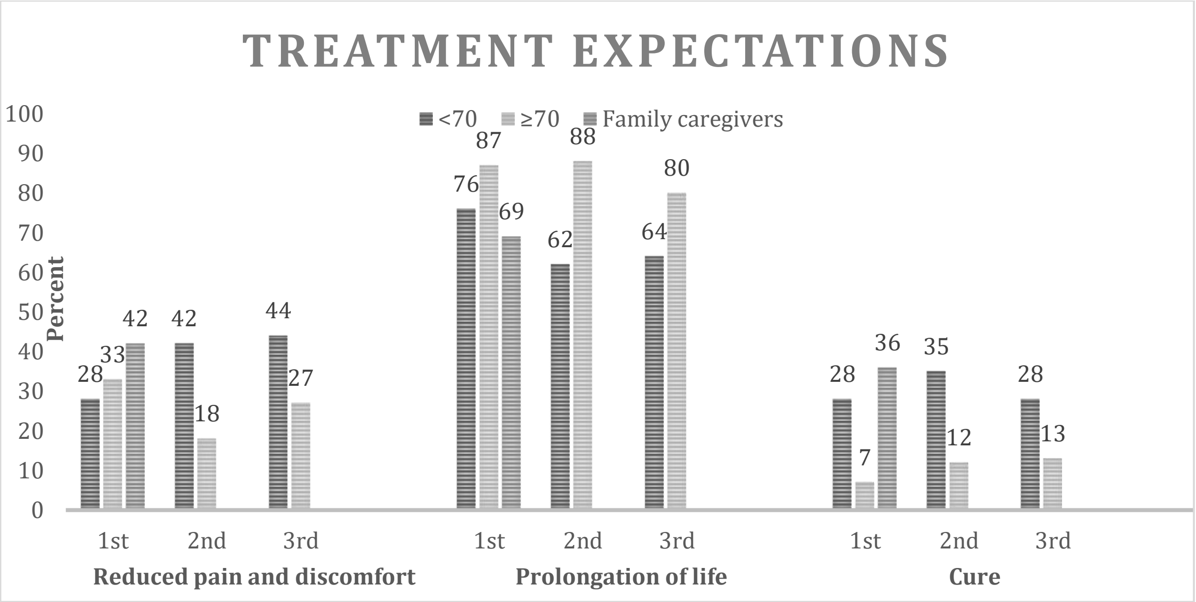

Figure 5. Treatment expectations among patients and family caregivers

Quality of life

In the results regarding QoL, there was no statistically significant difference in the interaction term of QoL and time (*p* = 0.83) between the two age groups. However, the overall mean QoL scores decreased significantly over time among all patients from 73.2 at first cycle to 70.5 at third cycle (*p* = 0.02). Nevertheless, it was not clinically meaningful [25]. Likewise, we did not find any statistically significant differences between the two age groups in QoL domain analyses. See **Figure 6** for overview over FACT-G total scores.

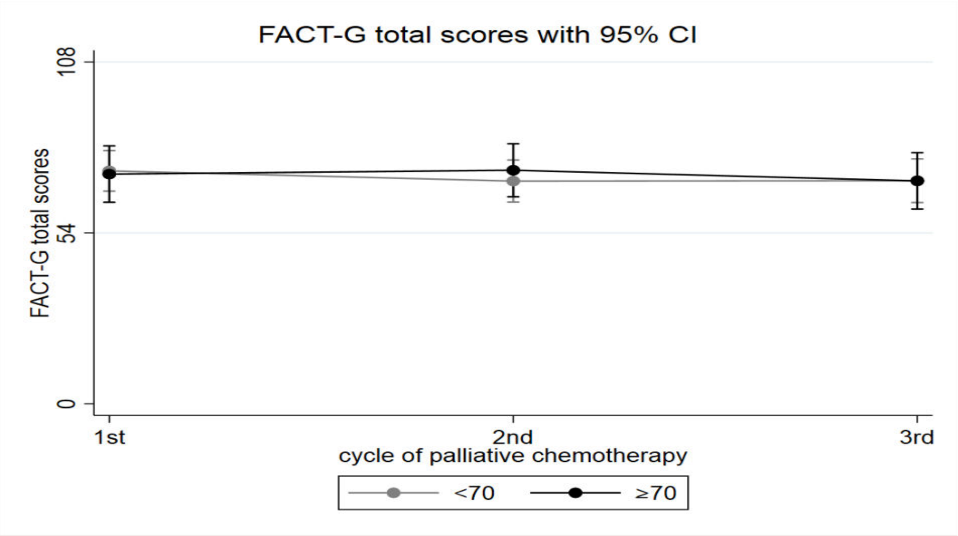

Figure 6. Overview FACT-G total scores

Study 2: A systematic integrative review

Aim

The aim of the systematic integrative review was to review current evidence of nurses' involvement in end-of-life discussions with incurable cancer patients and their family caregivers.

Research questions

What are nurses' perspectives on their involvement in end-of-life discussions - including barriers and facilitators - with patients with incurable cancer and their family caregivers?

Methodology

Systematic integrative review

The study was carried out as an integrative review inspired by the methodology developed by Whittemore and Knafl [120]. The integrative review follows the same principles for a systematic review, however the difference is that the integrative review are described as one of the broadest review types, as it includes both quantitative and qualitative research data [120]. The methodology follows: 1) literature search stage, 2) data evaluation stage and 3) a data analysis stage [120].

Methods

Before initiating the integrative review, it was registered in PROSPERO (CRD42020186204, https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=186204). PROSPERO is an International database that entails protocols to registered systematic reviews [121]. PROSPERO also gives transparency through the review process, as all steps and progress are continuously updated through the process. It is also a quality check, when a systematic review is published in PROSPERO, as the protocol are reviewed by the PROSPERO team before the protocol is published on the PROSPERO site [121]. The integrative review was conducted and reported in line with Preferred Reporting Items for Systematic Reviews and Metaanalyses (PRISMA) [122]

Data collection

Literature search

T.I. searched in four databases: CINAHL, Medline, Embase, and PsycInfo the 17th of June 2020. The search started in CINAHL, where keywords and the thesaurus were identified. According Whittemore and Knafl this is one of the most important steps when carrying out a systematic integrative review [120]. This process was time consuming and for over one month the keywords where adjusted and tested in the databases, discussed with my supervisors and with an experienced librarian (Mette Brandt) who supervised the testing of new keywords and combinations. The search was very challenging. For example, in the beginning a search was focused on only incurable lung cancer - a very narrow search, but this resulted in no articles. Afterwards we adjusted the search and included all patients with incurable cancer. There were also some challenges in the search word "end-of-life discussions" as we found out that plenty of synonyms exists, and they are all used in different context and with different meanings. That it also why we chose to search with a broad range of synonyms, such as "advance care planning". The search was after the first search in CINAHL adapted to the remaining databases. See **Paper 2, Table 1,** for Search strategy in CINAHL. T.I. and K.B.D. screened n=3271 articles for eligibility, first screening titles and abstract for relevance, inclusion/exclusion criteria and research questions. See **Paper 2, Table 2** for inclusion and exclusion criteria. Title and abstract screening were carried out in Covidence, a screening and data extraction tool helping to order and systemise articles whilst screening [123]. Afterwards 74 studies were included after title and abstract screening and they were all extracted into a classification system in Excel to systematise the full text reading process, studies were divided into qualitative, quantitative, and mixed methods studies to foresee the process.

Data evaluation

After full text screening, we included in total 15 articles and a data evaluation/quality appraisal was carried out with an approach inspired by Hawker et al [124]. The framework was based on ten criteria: 1) title and abstract, 2) introduction and aims, 3) methods and data, 4) sampling, 5) data analysis, 6) ethics, 7) bias, 8) results, 9) transferability or generalisability, 10) implications and usefulness [124]. Scores for each criterion range from 1 (low quality) to 4 (high quality), and the total possible score range for each study was 10-40 points. In case of any doubt during the quality appraisal, these doubts were discussed with the supervisors.

Data analysis

The data analysis was inspired by the approach of Whittemore and Knafl, which allows inclusion for both quantitative and qualitative articles [120]. The data analysis consisted of four steps [120]. The process was inspired by the phenomenological hermeneutic approach where I approached data with and open mind, but hermeneutically worked back and forward from themes to data and data to themes to reach a new understanding.

1) *Data reduction:* In the first step all data (from primary sources) were systematised in sub groups (quantitative and qualitative articles) just as in the data full text reading stage mentioned above [120]. This was practically carried out in two documents in word.
2) *Data display*: The second step consisted of coding the sub-groups. This was done by reading all primary sources several times, and high-lighted similarities across data, with the research questions

in mind. All relevant data (words, sentences, and quotes) from the primary sources, from each sub-group, were extracted to new word document – one for the qualitative articles and one for the quantitative articles. This made it easy to analyse and compare data within each sub-groups and put them into themes.

3) *Data comparison*. In the third step, codes were compared across the sub-groups to form themes. As described by Whittemore and Knafl, this was a creative and iterative process, were I continually went back and forward to reread data, when new ideas, but this process was also to secure that the ideas was found in the data [120].
4) *Conclusion and verification:* In the last step, before the final conclusion, Whittemore and Knafl recommends all themes are compared to the primary sources to verify the findings [120]. This was practically done when reading all articles through and comparing the themes to see if I could recognise the themes developed through the analysis.

Results

The full results of this study are presented in paper 2 [125]. The results section includes a summary of the main results. Of 3271 references, n=74 researched were initially read, and of those in total n=15 articles were included. See **Paper 2, Figure 1** for flowchart. N=12 qualitative and n=3 quantitative articles were eligible for the review. None of the included studies were excluded after quality appraisal. See **Table 2** for short overview of the included studies and results of quality appraisal and **Appendix 6** for detailed results of quality appraisal. There were found a total of four themes in the data analysis: 1) *Nursing roles;* the advocating, supporting and reframing roles, and an undefined task e.g., in medical consultations, 2) *Trust building,* 3) *Nurse competences* and 4) *Medical issues.*

In summary results presented that the nurses had defined roles in end-of-life discussions, as well as some more unclear tasks in the discussions in some situations. They advocated, by being an intermediary between patients and oncologist. They supported patients by for instance bringing a tissue, holding a hand, or just listening. In the reframing role they additionally had a responsibility for bringing attention to the stigma around palliative care. When analysing the data, it was also found that the nurses was unsure of who should initiate end-of-life discussions. Furthermore, the themes also revealed that facilitating factors for the nurses to be involved in end-of-life discussions were when they knew the patient and families. Even though, the families sometimes were seen by the nurses as challenging and time consuming and was described a barrier to initiate end-of-life discussions. Thus, education, experience, and competences were important for nurses to engage in end-of-life discussions. Finally, the data analysis revealed that a barrier to initiate end-of-life discussions was the focus on medical issues or future treatments by the patient, family, or physician.

Author	Year	Article	Country	Total score - Quality appraisal
Broom et al.	2015	Negotiating Futility, Managing Emotions: Nursing the Transition to Palliative Care	Australia	34
Broom et al.	2016	Nursing futility, managing medicine: Nurses' perspectives on the transition from life-prolonging to palliative care	Australia	33
Laryionava et al.	2018	"Rather one more chemo than one less…": Oncologists and Oncology Nurses' Reasons for Aggressive Treatment of Young Adults with Advanced Cancer	Germany	30
McLennon et al.	2013	Oncology nurses' experiences with prognosis-related communication with patients who have advanced cancer	USA	33
McLennon et al.	2013	Oncology Nurses' Narratives About Ethical Dilemmas and Prognosis-Related Communication in Advanced Cancer Patients	USA	34
McCollough et al.	2010	A model of treatment decision making when patients have advanced cancer: how do cancer treatment doctors and nurses contribute to the process?	New Zealand	29
Mohammed et al.	2020	"I'm going to push this door open. You can close it": A qualitative study of the brokering work of oncology clinic nurses in introducing early palliative care	Canada	35
Pettersson et al.	2018	Ethical competence in DNR decisions -a qualitative study of Swedish physicians and nurses working in hematology and oncology care	Sweden	36
Pettersson et al.	2014	Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care	Sweden	37
Rylander et al.	2019	Significant aspects of nursing within the process of end-of-life communication in an oncological context	Sweden	32
Tariman et al.	2016	Oncology Nursing and Shared Decision Making for Cancer Treatment	USA	24
Valente et al.	2011	Nurses' perspectives of challenges in end-of-life care	USA	22
Blazeviciene et al.	2017	Oncology nurses' perceptions of obstacles and role at the end-of-life care: cross sectional survey	Lithuania	36
Boyd et al.	2011	Nurses' Perceptions and Experiences with End-of-Life Communication and Care	USA	27
De Angst et al.	2019	Should we involve patients more actively? Perspectives of the multidisciplinary team on shared decision-making for older patients with metastatic castration-resistant prostate cancer	Netherland	33

Table 2. Short overview of the included studies and results of the quality appraisal

Study 3: A phenomenological hermeneutic study

Aim

The aim of this study was to investigate current nursing practice related to end-of-life discussions with patients with incurable thoracic cancer and their family caregivers from the perspectives of nurses, patients, and family caregivers in an oncology outpatient clinic

Research question

What is the current practice for end-of-life discussions patients with incurable thoracic cancer and their family caregivers in an outpatient oncology clinic from the perspectives of patients, family caregivers, and nurses?

Methodology

The study combined different methodologies; participant observation, informal interviews, formal interviews and focus group interviews with both patients, family caregivers and nurses. This combination of methodologies was used as it could give insight into the current practice at the outpatient clinic and give insight into the patients' families and nurse's perspectives of this practice.

Participant observation and informal interviews

Participant observations were used to investigate the current nursing practice at the outpatient oncology clinic, and likewise the informal interview was used to explore both patients, family caregivers and nurses' perspectives of the current practice. The participant observations were guided and inspired by the work of Kristiansen and Krogstrup [126], and Spradley [127]. Participant observations can be used to gain insight into any culture [127]. Furthermore it is a suitable method when looking at how humans act through interactions [127]. A researcher carrying out participant observations must be a part of the actors life, observe and talk to them and interpret these situations go gain an understanding of their life's and perspectives [126, 127]. As described earlier it is important in qualitative research and participant observations to reflect on how much the researcher is involved in the observations [126, 127]. Spradley talks about five types of participation, see **Figure 7.** From high degree of involvement to no involvement [127]. In the current study, I mostly worked with moderate observation, were Spradley describes the moderate observer as a researcher trying to balance between being an insider and outsider – to participate and observe. See reflections in the Method section on page 49. However, in a few situations I participated more actively, for example when initiating the informal interviews.

DEGREE OF INVOLVEMENT	TYPES OF PARTICIPATION
High	Complete
	Active
	Moderate
Low	Passive
(No involvement)	Nonparticipation

Figure 7. Types of participation

Own illustration - inspired by Spradley

Kristensen and Krogstrup also states that the research needs to balance between being close to participants and not being too close to the participants, but there are no clear rules or clear methodology of how to practically do participant observation [126]. Thus, Kristiansen and Krogstrup, and Spradley describes three kind of observations – descriptive, selective and focused observations [126, 127]. The first observations I approached the participants with more descriptive observations and moved through more selective observations when I had gained more knowledge on the practice and routines. Observations were also guided by Spradleys observational guide [127]. Examples of questions that guided the study: Who was present? What did they talk about? What did they do? [127]. Informal interviews were also used and they can advantageously be combined with participant observations [126]. Informal interviews are defined by Spradley as a kind of friendly conversation, however a friendly conversations with an agenda [127].

Participant observations and informal interviews were documented with field notes. Field notes must be as detailed as possible, and all observations, experiences and reflections should be written down [126, 127]. The field notes must be descriptive, though Kristiansen and Krogstrup states that the field notes are not the reality but the researchers interpreted reality [126]. There are two types of field notes: condensed which entails words, phrases, sentences and expanded field notes, where the researcher fill in all possible details. I worked with both types of field notes. See **Appendix 7,** for example of field notes. Spradley also states a fieldwork journal must be filled out, which represents ideas, reactions, and feelings from others [127]. During the study period I typically used this fieldwork journal like a diary, and wrote down all my ideas, mistakes, reflections and the problems I faced, which were practically done in a word document after every observation or informal interviews.

Qualitative interviews

As the research questions seeks to gain in-depth knowledge on both patients, family caregivers and nurses perspectives on end-of-life discussions, the qualitative interview is a useful approach [128]. According to Kvale and Brinkman the characteristics of the qualitative interviews is to describe and understand a specific phenomenon of interest and gain in depth knowledge on the subjective perspectives [128]. Kvale and Brinkmen's approach guided the study when making the interview guide, and they also inspired me with their different kind of questions, such as introducing, follow up and probing questions [128]. See **Appendix 8** for interview guides individual/joint interviews and **Appendix 9** for interview guides focus group interviews. In a qualitative interview, knowledge is generated in an interaction between the researcher and the participant [128]. The phenomenological hermeneutic underpinned the way of interviewing, analysing and interpreting data. Interviewing was inspired by the phenomenological and open approach and the process of analysing and interpreting data were inspired by the hermeneutical way of thinking.

The focus group interviews were used to explore clinical practice from the perspective of the nurses, and the process was guided by the approach described by Doody et al. [129, 130]. They describe that focus group interview is especially useful when investigating complexities of a practice, integrating different views [130], and when investigating a focused phenomenon, where there is a lack of knowledge on a specific topic [130]. This was exactly what we wished for when inviting the nurses into the focus group. Doody et al. suggest a purposive sampling where the participants are chosen based on their knowledge, and the size of the focus group can vary from 4-12 participants with a duration of approximately 1-2 hours [129, 130]. They have outlined some important aspects to consider when conducting a focus group, for example: the size of the room, location away from noise, telephones should be unplugged, tell participants that the interview will be recorded, group dynamics (for instance, the moderator should give all participants an opportunity to talk) and role of moderator, such as having prepared an interview guide and encourage discussion between the participants [129]. See reflections in the "Method" section on page 47.

Methods

As described the data was collected in a combination of participant observation, informal interviews, individual or joint interviews and focus group interviews. Patients, family caregivers and nurses were recruited from the Department of Oncology at Odense University Hospitals between August 2019-June 2020. See description of setting in the section "Setting" on page 29.

Participants and data collection

Participant observation and informal interviews

Patients diagnosed with incurable thoracic cancer (non-small-cell lung cancer, NSCLC, small-cell lung cancer, SCLC, or mesothelioma) and were about to start 2nd line palliative chemotherapy were included. The family caregiver who accompanied the patient was also included if the patient consented. The oncology nurses in the outpatient clinic were included regardless of their experience as an oncology nurse.

Just as described in study 1, patients were screened in the booking system "Mosaiq Schedule", where it was possible to find a schedule over patients course of treatment including dates and time for the next visit in the outpatient clinic. Patients and the family caregivers were included at their first appointment in the chemotherapy clinic, only a day after they had talked to the oncologist and were told that their cancer had progressed. They were then informed about the study and gave consent to participate in both participant observations and interviews. The day we wanted to include a patient and the family caregivers T.I. met up in the outpatient clinic and found the nurse who were scheduled to give the patient chemotherapy. The nurses were informed about the study on team meetings and gave written consent to both attend participant observations and focus group interviews after the team-meetings. Even though all the nurses were already included in the study, I wanted to secure that my attendance was acceptable with them. See **Appendix 10** for participant information for patients, family caregivers and **Appendix 11** for participant information for nurses. When doing participant observations in the medical consultations, I found the oncologist who should run the consultation, to secure that my attendance was ok with them, even though they were not included in the study. With the system theory in mind, it was a challenge to observe without including the oncologists perspective, but it was necessary because the oncologists at the department did not wish to be a part of the study. During the observations I only focused on the interaction between the patients, families and nurses, acknowledging that the oncologist has affected the way they patient, family and nurses communicated.

Participant observations included all situations where patients, family caregivers, and nurses interacted, e.g., patients receiving chemotherapy, conversations between patients, family caregivers, and nurses, and medical conversations. I observed patients and their family caregivers up to four times during treatment: (a) when initiating the first series of palliative chemotherapy, (b) when receiving the second series of palliative chemotherapy, (c) at follow-up consultations with the oncologist and nurse, and (d) when receiving the third series of palliative chemotherapy. See **Figure 11** below for illustration of the process, where it is illustrated that participant observations are carried out when the patients received treatment in the chemotherapy clinic and at the follow up clinic. As described earlier, the oncologist did not wish to participate in the study, but they agreed I could observe during the medical consultation, if the focus was only on the patient, family and nurses interactions.

In the chemotherapy clinic patients received their chemotherapy in a four bedded room, but in one of the rooms there were 4 chemotherapy chairs instead of beds. The rooms were the same size. Between the beds there was a curtain that could be used so the patients and family caregivers could have a little privacy.

When I started the study, I also had to establish assess to the Department. This was a challenge because I had not been employed at the Department of Oncology before initiating this PhD study. This was a long and time-consuming process because none of the nurses knew me. I really spend a lot of time in building trust, just being present, spending a lot of time in the outpatient clinic and asking a lot of questions. I started to approach the observations in my private clothes; I believed that I would approach as the "researcher" and not the nurse. After talking to another PhD student doing participant observations in another outpatient clinic, I was convinced that the patients and family caregivers would ask me about things such as chemotherapy and other questions related to their treatment if I had my nurses uniform on. However, I experienced this to be difficult, the patients and family caregivers did not open up, and the nurses rather excluded me when wearing my own clothes. The informal interviews I initiated in my own private clothes as a "researcher" were distanced, and I had a feeling that I was not "let inside" the patients and family caregivers' lives. I also felt it was awkward to wear my own clothes. After only three observations, I changed my mind and after discussing this concern with my supervisors, I started wearing a nurses uniform. This was eye opening, and in only a couple of days I felt like "one of the nurses". Suddenly the nurses invited me to take a piece of candy and a cup of coffee or asked me if I could help them with small practical tasks. The atmosphere was more relaxed. It was suddenly more natural to go in and out of a conversation when there was time and when the nurses e.g., left the room to get something. It is described by Kristiansen & Krogstrup that clothes, language and behaviour can have a huge influence on the relationships you are able to build up during the observations [126]. However, they do not recommend to wearing e.g., own clothes or uniform when doing observations, but they describe that to build up a relationship that is a reflective process, and it was. I continually reflected over my behaviour, language and role in the field when doing observations.

When starting study 3, participant observations were very broad, and I often placed myself on a chair the hallway where patients, families, nurses and physician walked by to get to know the outpatient clinics routines. Afterwards the observations were more selective, and I only attended when it made sense to the study for instance in the chemotherapy clinic. As an inspiration to what was important to observe in both the broad and selective observations I was inspired by Spradleys observational frame which included observations of the: space, object, activity, event, time, actor, goal and feeling [127].

Example questions guiding observations included: Who was present? What did they talk about? What did they not talk about? What did they do? [127]. Spradley writes that it is important to be aware of role of the researcher when doing participant observation [127]. All patient, families and nurses were aware of my role as I made this explicit to all when introducing the study - I was a researcher doing observations and I mostly had a moderate role, as described by Spradley. As mentioned earlier it was a role tried to balance by being an insider and an outsider. This meant that sometimes I was sitting on a chair in a corner, other times I suddenly had a more active part during treatment, although it was not planned. It was also a pragmatic approach where I tried to fit in, and I did whatever I felt was the most appropriate in the given situation.

The observations were supplemented with informal interviews. By doing this, it became possible to follow up with questions regarding the patients, family caregivers and nurses' behaviour/conversations during the observations. As mentioned an informal interview are by Spradley defined as "a kind of friendly conversation" [127], which I very much felt that it was. Before initiating the informal interviews with patients, I always asked if they had the energy to talk to me. They always had. However, two times I had to withdraw because patients became very tired and needed to rest during the infusion of palliative chemotherapy. Questions that were raised through the informal interviews could be related to what I had just observed in the interaction between the nurse and the patient and/or the family caregiver. Informal interviews were always conducted when patients received palliative chemotherapy. Sometimes the nurses were delayed by other tasks and in these situations, I often called in the patients and then we were able to have more informal interviews during one visit at the outpatient clinic. When the nurses had ended the chemotherapy infusion, there was often time for me to talk to patients and family caregivers and the conversation often started with small talk, for example small talk about their children and grandchildren. It became natural and possible in between this small talk to delve into what I had observed in practice for instance to ask what was in my interest as a researcher and shortly after returning to the more friendly conversation, for example asking to their child or grandchildren. Sometimes I had reviewed previous observations I had previously completed and had identified some areas I wished to go into if there had not been an opportunity at the last observation. Other times, new observations arose in the observations that made me curious and thus inquired as to when patients were receiving chemotherapy. It was very challenging to conduct informal conversations with the nurses due to work pressure and they did often not have the time to talk. A couple of times it was possible to catch one of the nurses for a short conversation lasting 2-5 minutes.

Field notes were written down immediately after the observations and informal interviews, but seldom during the observations, because I didn't want to disturb. Often, I went back to my PhD office, placed situated only one minute from the outpatient clinic where the field notes were expanded, and more details written down. Only a couple of times I had the opportunity to write field notes during the observations, and usually only during medical consultations where I was placed behind both patients, families, nurses and the oncologist. The field notes were written down in a small notebook, in short sentences or keywords. In addition, as recommended by Krogstrup, Kristensen and Spradley [126, 127]. In total 35 pages of field notes were conducted.

Individual and joint interviews

Individual and joint interviews, were carried out as semi-structured interviews guided by the work of Kvale og Brinkman [128]. The individual and joint interviews were conducted with patients and/or their family caregivers. Morris argues that the way an individual interview and joint interviews differs are because the participant know each other in advance, and it can have an effect on the answers [131]. Morris states there are factors a researcher should be aware of when conducting joint interviews, for example married couples can withhold some experiences they do not wish to talk about [131]. This situation I experienced once by interviewing a married couple, where it was difficult to get in depth descriptions, because the wife did not seem comfortable in the situation and answered very briefly and in a hurry. The patients and/or families decided the place, time, and type (individual or joint) for their interview. The interviews were held in the patients' home, at the outpatient clinic, or by telephone or FaceTime, mainly due to covid-19 situation. This affected the interviews, and I had a feeling that the interview held in the home, was more relaxed, open, and nuanced compared to the interviews held at the department or over the telephone. The semi-structured interview guide consisted of questions about decisions during treatment, daily life with cancer and palliative chemotherapy, and experiences with end-of-life discussions at the outpatient clinic and at home with families. One family lacked resources to attend interviews, and another family attended only interviews and not the participant observations due to Covid-19. I always gave the participants my contact details after the interview and told them they could contact me anytime, if suddenly thoughts occurred, they needed to talk about. See **Figure 10** illustration of the process, where it is illustrated that individual and joint interviews were carried out during time between visits in the outpatient clinic.

Focus group interviews

Two focus group interviews were conducted with nurses during their regularly scheduled shifts. T.I. facilitated the focus group interviews and another PhD student (Lærke Tolstrup) and K.B.D. acted as co-moderator by monitoring the time and asking any follow-up questions. The focus group interviews were scheduled at the hospital, while they were conducted in the nurses' worktime. We followed a pragmatic approach, as it was very difficult to take nurses out of their daily program to participate in a focus group interview; Therefore, it was also only possible for four nurses at one time to take part in the focus group.

Doody et al. also report that even a small group can be used if they are willing to participate in the discussions and if they have thorough knowledge of the subject [130]. As described earlier, the room should be an adequate size, not too small or not to large [129]. This gave us some challenges due to Covid-19 situation. The interviews were planned to be conducted in a big meeting room in accordance with the Danish Health Authority guidelines for the Covid-19 situation. The interview guide was semi-structured and planned with inspiration from the work of Kvale and Brinkman [128]. Both focus group interviews started with a welcome from T.I., as a moderator of the interview, following an agenda for the focus groups interview. T.I. clarified the interviewers role through the interview (a listener, and asking follow up questions), and told participants what we expected from them (discussing with each other and not us). An interview guide addressed the study aim and consisted of questions about nurses' experiences with end-of-life discussions, challenges to and facilitators of end-of-life discussions, and timing and content of end-of-life discussions. The nurses were also presented to quotes from patients and family caregivers conducted in observations and interviews. See **Figure 8** of illustration of the process where it is illustrated that focus group interviews were carried out in the weeks between the treatments.

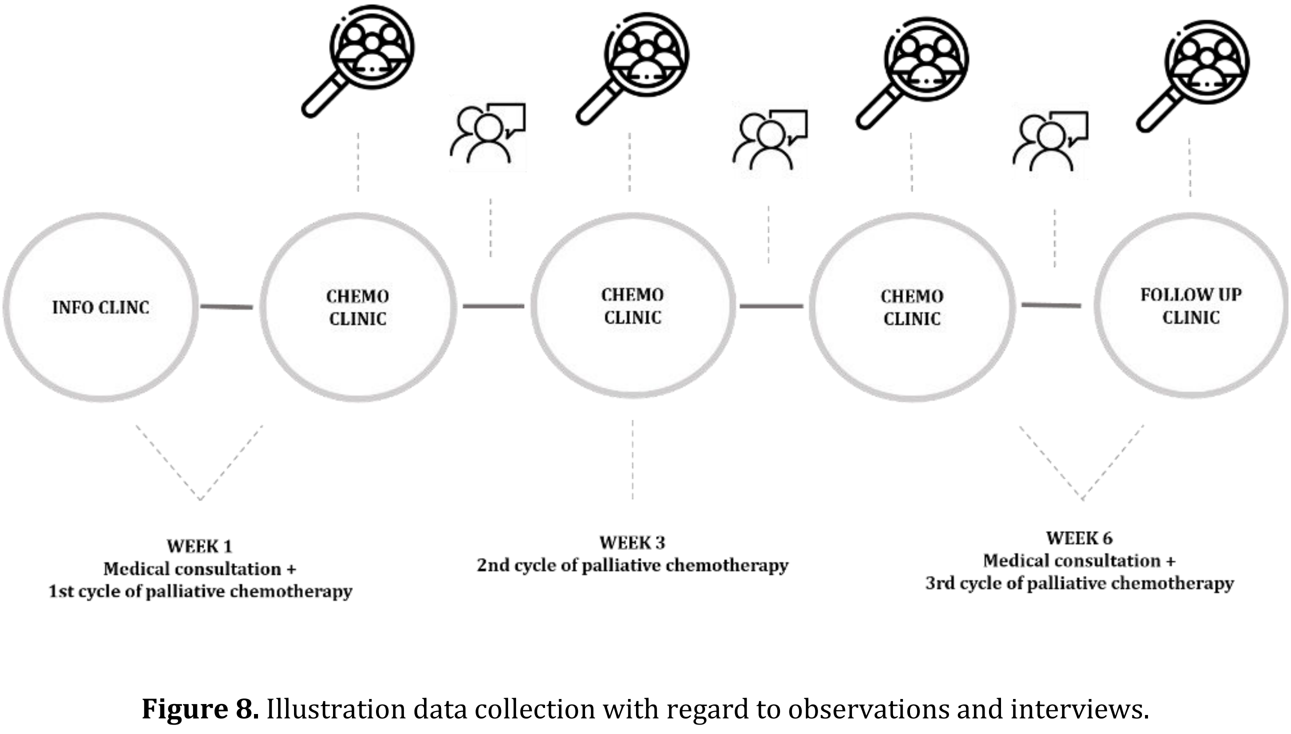

Figure 8. Illustration data collection with regard to observations and interviews.
The icons illustrate time of participant observations and interviews.

Data analysis

All data was uploaded into Nvivo12. This program helped organising all data, however the transcribed data were also printed and afterwards coded manually as it gave perspective. The data were analysed with a Ricoeur-inspired approach to analyse and interpret participant observations and interviews [132]. The approach consisted of three steps:

1) *Naïve reading.* Naïve reading involved transcribing the text and reading it through several times to obtain a first understanding of the text and participants' experiences. In this phase the researcher should be aware of what moves the reader [132], for example what initially touched me were the descriptions of a lack of continuity by both patients, family caregivers and nurses. The naïve reading also guided the structural analysis because it gave an initiate feeling of what was is important in the text. Then, in the structural analysis, this first feeling can be either confirmed or rejected.
2) *Structural analysis.* The structural analysis was the next step, but there was always a dialectic movement between the naïve reading and the structural analysis. The purpose of the structural analysis was to validate the first interpreted whole and understand the meaning of the text from what was said/observed to what was being talked about/what the observation was about. Based on their similarities and differences, meaning units were then merged to create themes. See **Table 3** for an example of the structural analysis, where the analysis process is illustrated, moving from the text pieces to meanings and finally themes.
3) *Critical Interpretation and Discussion.* The final themes are put into a broader perspective with for example existing literature and theory, and as Simony et al describes *"To move the findings from the individual to the universal level and bring fruitful perspective to nursing research and clinical practice"* [132].

Meaning unit (What is said/what is observed)	Units of significance (What is being talked about/What the observation is about)	Themes
"Of course, I can have a difficult conversation with a patient that I don't know, but I know I will miss something, because I don't know the story of the family and what is important to them" (N3).	It is important to know the patient and family before initiating a conversation	**Challenges in end-of-life discussions**
"I do not want to talk about difficult things with a nurse I do not know" (P7).	Patients don't want to talk to nurses if they do not know them	
"I often back out of the room while I talk to them, to illustrate that I do not have time to talk, it is awful" (N1).	Nurses' feeling of time pressure	
"We probably spared her (their daughter), but I do not think we should go and ... she should not go and think about it all the time, so therefore we do not talk about it" (P16).	It is difficult for families to initiate discussions	

Table 3. An example of the structural analysis of the theme "Challenges in end-of-life discussions"

Results

The complete results of this study are presented in paper 3. The result section includes a summary of the main results. In total, nine patients with incurable thoracic cancer, (NSCLC, SCLC, or mesothelioma), eight family caregivers and eleven oncology nurses were included. See **Paper 3, Table 1** for presentations of patients and family caregivers' characteristics, and **Table 2** for presentations of nurses' characteristics. Observations lasted from 30 minutes to 2 hours. A total of 21 participant observations were undertaken with a collective duration of 21 hours. A total of 25 short informal interviews lasting two to fifteen minutes were also conducted during participant observations. A total of 11 formal interviews were completed: five with patients, four with family caregivers, and two joint interviews. Two focus group interviews lasting 90 minutes each were conducted with nurses during their regularly scheduled shifts. See **Table 4** for overview of data collection – study 3.

Data collection method	Participant observations	Informal interviews	Formal interviews	Focus group interviews
Number of observations and interviews	21 observations of patients and/or family caregivers and nurses	25 informal interviews with: • 12 nurses • 8 patients 5 family caregivers	11 formal interviews with: • 5 patients • 4 family caregivers • 2 joint interviews with patients and family caregivers	Two focus group interviews with 3 and 4 nurses

Table 4. Overview of data collection – study 3

The data analysis resulted in three themes: 1) Content in end-of-life discussion, 2) Timing of end-of-life discussion, 3) Challenges in end-of-life discussions.

In summary, the themes described that end-of-life discussions focused on treatment, location of care, practical and economic concerns, and existential matters. End-of-life discussion were seldom initiated in practice, and patients and family caregivers had different needs for the timing of end-of-life discussions. Family caregivers found it challenging to initiate discussions with other family members, and the nurses also found it challenging to initiate discussions due to the physical environment, time pressure, and lack of continuity.

Ethical considerations

In this section considerations of ethics across the three studies are outlined. The next section is organised into three overall headlines inspired from The Ethical Guidelines for Nursing Research in the Nordic countries: *1) The researcher and the society, 2) The researcher and the profession 3) The researcher and the participants* [133]. The guidelines are developed on the basis of general International declarations, conventions and laws that regulates the research in the United Nations [134], The Helsinki Declaration [135], The Nuffield Council on Bioethics [136], The European Union [137], The Council of Europe [138], and at a national level in the Nordic countries [133].

The researcher and the society

Before initiating the PhD study the project was approved by the Danish Data Protection Agency (Journal no. 18/60988), in line with recommendations from The Ethical Guidelines for Nursing Research in the Nordic countries [133]. The study did not require approval by the Regional Committees on Health Research Ethics of Southern Denmark (Journal no. S-20172000-90). Approval to collect data was given by the head of the Department of Oncology at Odense University Hospital. Furthermore, all data in the published studies are available on request, and all data from the PhD study is published or submitted to international journals, in line with the ethical guidelines from The Ethical Guidelines for Nursing Research in the Nordic countries [133].

The researcher and the profession

It is a learning process to enroll at university as a PhD student, and according to The Ethical Guidelines for Nursing Research in the Nordic countries it states that all researchers without an in-depth knowledge on for example specific methods, must be supervised by experiences researchers [133]. During the PhD period I was supervised by experienced researchers, Karin B. Dieperink, Mette Raunkiær and Olfred Hansen. I must also mention Stefan Starup Jeppesen, the head of the Department of Oncology who was part of study 1. All professionals shared their enormous knowledge within the field of palliative care, quantitative and qualitative research. Furthermore, any researcher must comply the rules for authorship [133]. In all the three articles a section called “Author contributions” was carried out to ensure the roles in the articles transparent. The authorship roles were also discussed in meetings with all supervisors.

The researcher and the participants

The requirement concerning information

Oral and written informed consent were obtained after having carefully informed the patients and family caregivers in study 1 and study 3. Patients and family caregivers could withdraw from the project at any time, without any consequence for future treatment or stay in the hospital. To ensure anonymity patients and family caregivers were also informed that they were participating as a part of a larger project together with other families. Nurses at the outpatient clinic of the Department of Oncology were informed about the study at team meetings and gave written consent to both attend participant observations and focus group interviews after the team-meetings. Some participant observations would take place at medical consultations and the oncologist at the outpatient clinic was also informed about the study at team meetings and told that I would attend some of their consultations.

The requirement concerning confidentiality

All data must be stored safely [133]. The data was stored safely in REDCap, in SharePoint, in Nvivo12, and written consent was stored at the Department of Oncology, OUH. All names of participants were anonymised and coded with numbers in the final articles and in this thesis.

The requirement concerning the safety of the participant

During the study period there were many difficult and challenging situations I had to reflect upon. The Covid-19 situation positioned me as a researcher in a difficult situation. The Head of the Department opened for data collection, two months after the first wave of Covid-19; I was however concerned and had some thoughts about it. This was a very new situation for all, and we did not know how the patients would react if they were infected with Covid-19. I usually travelled by train to Odense University Hospital - met many people on my journey and could potentially bring the infection to the Department. The Ethical Guidelines for Nursing Research in the Nordic countries states that the researcher must have reflections of the safety of the participant, and interrupt or postpone the research [133]. While doing the data collection at study 1, I asked the nurses to hand out the questionnaires to the patients and I called the patients by phone the day after to tell them about the study. It seemed that some patients had isolated themselves during the period and the nurses had been told that the patients were afraid of getting infected by Covid-19. While I had included nine patients in study 3, I took the decision to stop the observations and asked the last two included participants to take part in the interviews by phone. This also meant that the rest of the participant observations that were planned to be carried out in in another outpatient clinic, were postponed, and the systematic integrative review was planned instead, as described in "setting".

Benefit and harms

The researcher must also consider both the beneficence and potential harm that the study might give the participants [133]. Some of the participants had individual benefits from the study and described how the interview made them reflect and discuss end-of-life matters that they had not previously talked about. Another situation that led me into a challenging ethical situation was during the interviews in study 3. Many patients were very sad due to their situation and found it difficult to talk about their situation. I continually had to balance between carrying out the interview or stopping. It was especially challenging in the telephone interviews, under the Covid-19 pandemic whilst I could not see or feel how the patients reacted, but I was not able to render any physical support by giving a tissue etc.; I felt it was unsatisfactory, and this may also have affected the data quality. I always gave the patients and family caregivers my telephone number after ending the interviews and told them they should call if they had some questions afterwards, but no one did. Before initiating the study, I had many considerations of how to approach the patient and family caregivers if they were vulnerable. All the patients during the study period received palliative chemotherapy – some patients had a relapse after surgery, while others at the time of diagnosis started palliative treatment. Patients were usually receiving treatment in the same room as other patients. Therefore, regarding study 3 the informal interviews were not performed whilst other patients and families were present, which also could have affected the data quality. In-depth questions that raised in relation to the participant observations were postponed and then asked at the semi-structured interviews. In relation to both the nurses and physicians, it was important to me, as a researcher that I did not create any discomfort or strain on the staff's daily work.

During the study period I was open about the purpose of the study and always tried to make sure that I did not interfere with the staff's daily workload by my physical presence. Even though I tried to think everything through before initiating the study, it became clear that conducting a study in a real-life setting was challenging. An example: As described I informed the oncologists about the study at team meetings, even though they were not a part of the study. One of the oncologists was on holiday leave when I presented the study, and the oncologist became very surprised by my appearance during the medical consultation. Before the consultation it was not possible to talk to the oncologist. The oncologist was surprised and talked to me in a very uncomfortable manner and asked me what I was doing in the consultation. The patient and family that I had followed on a couple of occasions went to the department because they were waiting to see if the patient's cancer had progressed further. The patient and family were affected by the way the oncologist approached me, and it had consequences for the conversation with the oncologist and their trust afterwards – they told me. This situation made me change how I prepared for every single participant observation. For example, I always talked to the oncologist before attending the medical conversations, to make sure my attendance was ok.

Discussion

The following section will start with a discussion of the findings following a discussion of the methodological considerations of the three studies.

Discussion of the findings

In this PhD study three studies with different methodologies were carried out. Study 1 included 48 patients and 36 family caregivers and found no significant difference in treatment expectations or QoL in patients <70 years and ≥70 years. However, a high percentage of patients and family caregivers expected a cure from the palliative chemotherapy. In study 2, the integrative systematic review included in a total of peer reviewed 15 articles, and found that the nurses had several roles in end-of-life discussions: supporting, advocating, and a reframing role. Barriers and facilitators for engaging in these discussions were identified, for example trust, competences, and medical issues. In study 3, 28 participants were included and concluded that end-of-life discussions focused on treatment, location of care, practical and economic concerns, and existential matters. The discussions were seldom initiated in practice, due to the physical environment, time pressure and lack of continuity.

Throughout this PhD study, the focus has mainly been on the nurses' involvement in end-of-life discussions, however palliative care focuses on both physical, emotional, social and spiritual aspects including patients QoL, decision making and end-of-life discussions, which seeks for an inter-professional approach [15, 72, 73]. Palliative care and end-of-life discussions are handled by many different professions in the health care system and this collaboration of professionals is essential to provide a holistic care for the patients with incurable cancer and their families [15].

Based on the above mentioned results, also presented in the three papers, the following section will present and discuss some of the main challenges the future health care system is facing in integrating palliative care into oncology at the general palliative care level. The discussion will be carried out on three levels, however, these will to some extent overlap:

1) Structural level
2) Educational level
3) Individual level

Structural level

Traditionally diagnosis and treatment, for example chemotherapy has been offered in hospital wards, but with the increasing ageing population, the hospitals need to find more efficient ways to treat and care for patients [139]. Likewise, there has been a reduction in beds offered in hospital settings in Denmark, as well in other parts of Europe, which when combined have led to more outpatient consultations [139]. Furthermore, patients live longer with chronic diseases [14] and therefore the need to integrate palliative care into hospitals and outpatient oncology clinics, collaborate inter-professional, coordinate and planning the care provided is more relevant than ever [14, 140]. In the context of this PhD study, diagnosis, treatment, and palliative care are carried out during short stays in outpatient settings and this is complex. There are, however some organisational and structural challenges in incorporating palliative care into outpatient oncology clinics as the treatment logics is still predominant, as previously discussed by Kaasa et al [14], and shown in the structure of the outpatient oncology clinic in **Figure 1**. It will be a challenge for a future health care system to connect the two different and conflicting logics [14]. New organisational structures must be considered in the health care systems that support the importance and integration of palliative care in outpatient oncology clinics. First of all, in paper 1 we asked patients systematically what their treatment expectations and QoL were, which were currently not part of clinical practice. Paper 1 furthermore reported no significant difference in treatment expectations between the age groups were, although a higher percentage of the younger patients <70 expected a cure. Likewise paper 1 didn't report any difference in QoL between the age groups, which is similar to the findings published in a recent study from 2020 [141]. Incorporating discussions of treatment expectations and QoL systematically in clinical practice may benefit all parties when making future decisions about treatment and care [30, 141]. In paper 3, barriers for executing end-of-life discussions, which can be considered as an early palliative care intervention, were identified. As described by both patients, families, and the nurses, it was a challenge that there was no room or time to have private conversations in busy outpatient clinics. Klarare et al likewise described the time factor as problematic in their study investigating team interactions in a specialised team [142]. Their results showed that with the existing conditions and resources the health care professionals did not feel it was possible to provide satisfying care [142], just in line with the results of paper 3, where the nurses did not feel they had the time to engage in end-of-life discussions due to many work tasks. In paper 2 and 3 it was found that continuity was of great importance, as trust was essential. Recently described in a study by Mok et al trust in the patient - health care professionals relationship with the patient and families, was described as a crucial aspect in palliative care [143].

As mentioned in the background section, it is recommended by The Danish Health Authority that palliative care, including end-of-life discussions should be offered as an inter-professional approach, and include the family [15]. Nevertheless, recommendations of how the different disciplines in the health care system should collaborate and how it should be implemented in practice are unclear and it is challenging to implement directly. According to Kaasa et al, it is difficult to see any patterns in the organisation of palliative care in Europe [14]. This leaves a responsibility to the individual organisations, leaders, and health care professionals to find ways to structure palliative care in their own clinical practice [14, 15]. From earlier studies we know that palliative care and also an inter-professional approach in the care provided are important for patients and their families [144]. Ferrell et al tested in a study from 2015 the effectiveness of an inter-professional team approach to patients with lung cancer in an outpatient setting [145]. Almost 500 patients were randomised to receive either standard care or an intervention with an inter-professional approach, and they found that the intervention group had better QoL scores, and even better completed advance directives, 44% vs. 9% [145]. A review from 2018 investigating the impact of inter-professional approach in palliative care concluded that the approach was beneficial [146]. For example, working in an inter-professional way affected the length of hospital stay, symptom management, physio social involvement, admission to intensive care units [146]. However, working inter-professionally is challenging, and according to Just & Nordentoft, many health care professionals providing palliative care at the general palliative care level work in a multidisciplinary way instead of inter-professionally [140]. For instance, when the medical secretary, the nurse and physician for example plan and coordinate the course of treatment for the patients who are going to receive palliative chemotherapy, then the individual disciplines perform their own specific tasks without talking about the specific patient and family. The physician prescribes chemotherapy, the nurse provide chemotherapy, the medical secretary plans the visits in the outpatient clinic. According to Gibbs et al, many health care professionals and leaders do not have knowledge of the concept of palliative care, and therefore do not embrace and use it in clinical practice [147]. This will be a challenge in future health care regarding palliative care in an inter-professional collaboration. Furthermore, a Danish mapping from REHPA showed that 85% of the hospital wards expected their patients might have a need for palliative care, however only 33% of the departments had clear instructions how to provide the care [23], which also calls for more priority for palliative care in hospitals. This is problematic, and it has previously been discussed that the reasons why some departments in hospital settings have clear instructions regarding palliative care, were because health care professionals had a special and personal interest in palliative care [148].

With regard to inter-professional approach as an integral part of providing palliative care in Denmark, the Danish Multidisciplinary Cancer Group of Palliative Care (DMCG-PAL)(In Danish: Dansk Multidisciplinær Cancer Gruppe for Palliativ Indsats), published in 2016 their results on a mapping of the current inter-professional collaboration at the general and specialised palliative care level [149]. N=61 different units were asked how they managed to work in an inter-professional way. The physical environment was found to be an important factor for working together in palliative care [149]. Some units had shared offices, which facilitated coordination of meetings discussing the patients [149]. However, the results were from specialised palliative care units [149], and evidence is lacking regard the benefit of shared offices at the general palliative care level. As described, Klarare et al have investigated team interactions in specialised palliative care and the results showed that organisational issues had a huge impact of the care delivered [142]. Furthermore, leadership was described as a structural issue, for example it was beneficial when the inter-professional team was led by only one leader [142]. Regarding the context of this PhD study, the different health care professionals have different leaders. The physicians have one leader, the nurses have another, the physiotherapist a third one, and so one. However, there is a lack of knowledge in this area, but generally the structural circumstance for providing palliative care is a future challenge to overcome. According to the Lancet Commission from Kaasa et al from 2018, there is a need to take action, and the commission suggest that International organisations should work together to discuss and compile recommendations on how to structure and integrate palliative care into oncology departments in hospitals [14].

Educational level

It is important to incorporate education in palliative care into oncology practice [14, 150]. In paper 1 discrepancy between patients and family caregivers treatment expectations, may point toward a need for more training in end-of-life discussions. In paper 2 it was furthermore described that the nurses lacked competences to engage in end-of-life discussions. Other studies have also described lack of competences for practicing palliative care in other health care professionals [151, 152]. Literature reports that education is important for practicing palliative care to provide the correct care for patients and families approaching end-of-life [150, 153]. However, there is a lack of training in palliative care in undergraduate and postgraduate education [150]. Harden et al concluded in an educational intervention study from 2017, including nurses providing palliative care, that education in palliative care led to more end-of-life discussions, as the nurses changed their behaviour, attitudes, knowledge and approach to palliative care [154]. Klarare found in a study investigating team interactions in specialised palliative care that none of the participants had received any formal education on how to collaborate inter-professionally [142]. This is like the nurses at the oncology outpatient clinic, who also stated in the interviews in paper 3, that they had not received any education in working inter-professionally, neither education in initiating or carrying out end-of-life discussions. This is thought provoking, when literature describes that it is complex to provide palliative care [140, 142, 144, 150]. In International and also Danish contexts, there has not been a tradition for palliative care training in undergraduate educations, for example in nursing, medicine and physiotherapy [155]. There is still a lack of mandatory training in palliative care at an undergraduate level, however work is being done to implement education in palliative care at undergraduate level. The Danish Health Authority, states in the Palliative Care Recommendations from 2017, that all undergraduate education in the area of health should receive palliative care training [15]. For example in 2016, the announcement regarding education of bachelor in nursing (In Danish: Bekendtgørelsen om uddannelse til professionsbachelor i sygepleje), palliative care was mentioned as a mandatory discipline [156]. Regarding this, palliative care is still quite new in nursing education, and it is still up to the individual educational institutions to decide to what extent the palliative care training should be offered. The amount of palliative care training often depends on key figures and teachers with a personal interest in the area. This is also applicable for the medical education, and this may also be an explanation to why some nurses and oncologists didn't initiate end-of-life discussions. There is still work to be done, for instance the announcement regarding the education in physiotherapy (In Danish: Bekendtgørelsen for uddannelse til professionsbachelor I fysioterapi) palliative care is not mentioned as a mandatory discipline [157]. This is problematic, and there may be a need for all undergraduates to be introduced to palliative care early in their career. Not even nurses and other health care professionals working in oncology settings receive any mandatory training in palliative care in Denmark. A project initiated by the British Medical Association found that physicians described that there was a lack of training and also support in end-of-life discussions [158], which is similar to the results in paper 2, were the nurses lacked training. DMCG-PAL have developed recommendations for postgraduate competences in palliative care across disciplines, for example for nurses, social and health assistants, priests, occupational therapists, physiotherapists, and music therapists [159-164]. However, recommendations for competences among physicians is missing. Physicians working in specialised palliative care often attend the Nordic education in specialised palliative care, however there may be a need to develop recommendations for competences for physicians working at the general palliative care level. Nevertheless, it still leaves a responsibility to the individual health care professional and the leaders to gain and plan how to achieve these competences [159-164]. A newly published report from the Danish Cancer Society from June 2021 states that: "*There is a need for improvement of palliative care in Denmark*" [165]. They especially describe that education and competences are two essentials ways to improve palliative care in Denmark [165]. As discussed in paper 2, reflections guided by the specialised palliative care team may promote the health care professional's knowledge, but also promote competences in end-of-life discussions, inter-professional collaboration, and competences in involving families. Frequently visits by specialised palliative care teams may also be a way to promote awareness of - and competences in end-of-life discussions including competences in how to initiate talks of treatment expectations, which are described as important in paper 1. Just & Nordentoft describes that it is through participation in a specific context that learning is developed [140]. In Denmark, work is being done by training key figures in palliative care, which should guide, educate and supervise colleagues [166]. An evaluation of the effort shows that the key figures are important in their daily practice and in guiding colleagues, however the key figures miss support from their leaders to carry out the work [166]. Not only health care professionals need education in palliative care [14]. A barrier for integrating palliative care into oncology, is the stigma around the concept [14], which is also presented in paper 2, where nurses had a role in clarifying the stigma around palliative care. Kaasa et al argue that communication with the public around palliative care is important for minimising stigma and for integrating palliative care earlier in the course of disease [14]. For example, palliative care can be provided alongside active treatment, and alongside curative intended treatment to relieve suffering, and not only in the last days of life. As earlier described paper 1 reported discrepancy between patients and family caregivers expectations, and in paper 2 and 3 it we found that it could be challenging to include families, which may be due to lack of competences in family involvement. In Denmark, there is neither any tradition for education in family involvement on undergraduate or postgraduate level. The International Association for Family Nursing (IFNA) have developed position papers for competences for nurses regarding family involvement [167-169]. IFNA encourage nursing educators to develop programs that promotes the care for families [169]. They also state that care for families seeks for an interprofessional approach, which is also in line with the palliative care recommendations [169]. As the family are important throughout the course of disease it be beneficial for all health care professionals providing care for incurable patients with cancer, to receive formal education in family involvement. Together with structural changes, education in palliative care and family involvement is a second factor that needs attention for improving palliative care in outpatient oncology clinics.

Individual level

Families are an important part of palliative care. In the findings reported in the three papers, it was found that it could be challenging to incorporate families into end-of-life discussions. With the systemic theory in mind and earlier research we know that it is important to include and improve the involvement of the families in palliative care, because illness affects all family members [76, 170, 171]. Earlier Danish studies, as well as international studies have reported that families are an important support during cancer treatment [172, 173]. However, a systematic mixed methods review study from 2020 reported that families expressed difficulties in talking together about end-of-life, because they wanted to protect each other [174], just as we found in study 3. The systematic review study also described similar to the finding in study 3, that not all family caregivers were ready to engage in end-of-life discussions [174]. This could also be a reason why the patient and family caregivers had different wished to expectations to the treatment, as described in paper 1. Involvement of families is complex, because both patients and families may have individual wishes [175], but fortunately there is an increasing focus on family involvement in research [176]. In a study by Ho et al from 2016 found that 70% of the included health care professionals where it challenged in end-of-life discussions, due to discrepancies between patients and family caregivers' understandings of treatment [177], which were also reported in paper 1. This finding is similar to findings reported in several other studies [27, 178-180]. In paper 3, it was described that the nurses really wanted to involve the families, and they felt it was their main task. Nevertheless, they did not systematically involve the families. In a study from 2017 by Shin et al, found that only 56% of oncologist supported involvement of families, despite both patients and family caregivers wishes to be involved [181]. This is in line with a study from 2018, by Laryionava et al, were it was found that the oncologist and nurse supported the involvement of families, nevertheless this did not lead to earlier involvement of the families [182]. There is a need to find more efficient ways in clinical practice to improve family involvement and there is still a lack of research of the area. However, family involvement matters and an interventional study including families in cancer care found that 90% of families experienced a decline in emotional suffering after talking to a family therapist [183]. The results from paper 2 also reported that a barrier for end-of-life discussions and family involvement could be the lack of role clarification. Furthermore this could be a reason why patient and family caregivers had different treatment expectations in paper 1 – end-of-life discussions may not be initiated due to lack of role clarification among health care professionals. With role theory from Lauvås and Lauvås the importance of clarifying roles in the collaborating team in the course of palliative care and in end-of-life discussions were discussed [184]. Who is responsible for carrying out end-of-life discussions and involving the families? Just & Nordentoft agree and states that palliative care requires that the team members, for example the nurses and the physicians, know the roles and diversity of one's profession [140]. According Just & Nordentoft, working inter-professionally also requires that some tasks are specialised, and easier to attach to a discipline than other tasks [140]. An example may be that there is no doubt that it is the physician who plans the treatment, and what kind of specific treatment the patient should be offered. Another example may be that it is the nurses who provide the chemotherapy. However, when talking about end-of-life discussion and family involvement, it is a grey area, as the discussion could be carried out by both the physician and the nurses, or even a third party, for example a phycologists. It is important to clarify who is responsible for carrying out end-of-life discussions and involve the family, because when no one thinks it is their specific task, they this may not be initiated. This was found in study 3, and also indicated in paper 1 where patients and family caregivers didn't have the same expectations to palliative treatment. Likewise, the nurses in paper 2, were not sure of what task and role they had in end-of-life discussions and especially when the oncologist also was present during the consultation. Similarly in a study by Pfeil et al from 2015 investigating the physicians experiences in end-of-life discussions, it was found that when patients had unrealistic expectations of their treatment, some physicians responded by not initiating end-of-life discussions, which meant that they were not carried out [185]. Relating to this PhD study, it means that for example nurses, physicians, and other important health care professionals during treatment must discuss and get to know each other's disciplines, its strengths, and their individual roles if palliative care is to succeed.

The nurses, with support from other health care professionals, are in a good position to initiate and facilitate communication and in a study by Glajchen et al from 2017 it was found that carrying out end-of-life discussions and involving the families lead to more satisfaction among not only the patients and families but also a greater satisfaction among the nurses [186]. This might be important, as paper 3 also reported that the nurses felt guilty, when they did not have the time to initiate a conversation with patients and families and sometimes had to *"back out of the room to illustrate that they don't have time"* as described in the result section in paper 3. Harrison et al investigated burn out among palliative care clinicians in a study from 2017, and found that if the health care professionals are not able to provide the care they wish this might lead to burnout [187], which is well known among health care professionals working in oncology and palliative care [187-189]. Burnout has a negative effect on the care provided and Harrison et al also described that organisational factors can be a reason for burnout, because health care professionals often must act in contradiction against ones own ethical beliefs [187]. This is further supported in a newly published Danish study from 2021, which discuss's factors that could increase the risk of burnout in specialised settings, for instance lack of continuity, inter-professional teamwork or lack of supervision [188]. This means, that outpatient oncology clinics must reconsider the organisation of their work, whilst burn out is a clear symptom of structures that do not work in the current practice. Health care professionals must also advocate for palliative care including the importance of end-of-life discussions and family involvement. This may provide a culture where palliative care is seen as an integral part of the care provided. As described in "Educational factors", key figures that advocate for palliative care could be important when trying to integrate palliative care [166]. A study investigating physician's beliefs about end-of-life communication with patients and families found that there were major differences in beliefs of the included physicians [190]. Health care professionals must investigate their own beliefs, thoughts and values when providing palliative care and involving families, just as described by Wright and Bell [191], because it can affect the care provided [192]. Together with structural changes, education and individual/cultural changes is essential for improving the palliative care in outpatient clinics in hospital settings.

Methodological considerations

In the following section methodological considerations of this PhD study will be carried out, including discussions of methodological strengths and weaknesses. This PhD study has combined both quantitative and qualitative data and there are different approaches to discuss the quality of the studies, within the different traditions [193, 194]. Terms as validity, reliability and generalisability are often associated with obtaining quality in quantitative research and by others researchers seen as not appropriate to discuss the quality of qualitative research [193, 194]. However, the terms validity, reliability and generalisation are by others described as suitable for assessing the quality of both quantitative and qualitative research [128, 193, 194]. In the following section a discussion of the terms validity, reliability and generalisability of the studies will be carried out, inspired by the understandings described by Polit and Beck [193], and Kvale [128]. First methodological considerations of the overall PhD study will be carried out, following an examination of the methodological considerations regarding study 1, 2 and 3.

In this PhD study both quantitative and qualitative approaches were used. Since the late 1980s there has not been a tradition of combining different research approaches like the quantitative and qualitative, as they have been seen as incompatible due to their different epistemological views [106]. Yet there has been an increasing interest in combining quantitative and qualitative approaches, because it is argued that it can be a strength of the findings [106]. However, there are some strengths and limitations that are important to discuss regarding the overall PhD study. According to Frederiksen et al., there are not a stringent way of combining the two research approaches, and they can be integrated in different ways, for instance in theory, the design, the method, the analysis or in the discussion [106], where the overall PhD study mostly integrated the findings in the interpretation, which is also gives strength to the overall findings according to Frederiksen [106]. First of all, study 1, gave some interesting findings of differences in treatment expectations between patients and family caregivers and these findings would not have been possible to find using for example only interviews. However, as surveys often include only brief response opportunities and it do not give much in-depth knowledge [193]. It would have increased the validity of the overall PhD study if we had combined this data with for example interviews, because it allows us to cross check the findings and we could make sure findings were accurate and well-founded [106, 195]. Validity is defined as: "*The degree to which inferences made, are accurate and well-founded; in measurement, the degree to which an instrument measures what it is intended to measure"* [193]. Before initiating the study, we discussed the benefit of including and following the same patients and families in study 1 to 3. As the patients were in a vulnerable situation T.I. asked a few patients and families what they thought about this. They told me that they wanted to, but it would be too overwhelming to participate in a second study. With regard to cross check or validate data, it was however also a strength to the results of this PhD study that the systematic integrative review was carried out instead of including patients with pancreatic cancer, because we were able to validate the findings in study 2 and 3, for example with regard to the challenges the nurses experience with family involvement in end-of-life discussion. In contrast it would also have given an opportunity to strengthen the generalisability of this PhD study if we had included the patients with pancreatic cancer, because we would have been able to compare two different group of patients, as Polit and Becks definition of generalisability is: "*To which degree the findings are true for a broader group than study participants*" [193]. It is a strength to mix perspectives of different participants studies [193, 195] which was done across the three studies when including both patient, families, nurses and oncologists. Furthermore, palliative care is an inter-professional approach and perspectives of all health care professionals are important – not only the nurses. There is only reflections left to discuss why the oncologist did not want to be a part of the study – maybe it was because they didn't know me, maybe they felt it was an issue to participate in the observations whilst having difficult conversations. In hindsight, I would have spent some more time in the clinic to building up trust and to getting to know the oncologists before initiating the study, because it would have provided more strength to the findings of the entire PhD study if the oncologists were also included.

In study 1, a question on treatment expectation was developed to assess patients and family caregivers treatment expectations. This was complex, as there did not exist a validated tool assessing treatment expectations. According to Polit and Beck this can be a limitation, as they define the reliability as: "*the degree to which a measurement is free from measurement error – its accuracy and consistency*" [193]. As described by Drennan et al, one word that may make sense to one group, may not be the same in another group [110]. Therefore, a question inspired from existing studies was developed and adapted it to the context of this PhD study. An example in our study could be the word "cure", but to make sure the question would capture the full context and to make sure the patients and family caregivers did understand the meaning of the question, it was pilot tested, which can be considered as a strength to the reliability and validity [110]. One could discuss if the quantitative methodology was the most appropriate way to investigate treatment expectations. By choosing a qualitative approach more varied descriptions and in depth and nuanced knowledge of the patients and family caregivers expectations about the possible answer would have been reached. However, it would not have shown the discrepancy about treatment expectations that we found in this study. This study was explorative, and this gave good and basic information and knowledge of the patients and family caregivers beliefs, and interesting differences between patients and family caregivers. Patients QoL were assessed with the FACT-G questionnaire, which is a validated tool and widely used questionnaire [114], and this strengthens the validity and reliability of the study [193]. As described earlier, this study was explorative and with only 48 patients and 36 family caregivers. Patients with thoracic cancer, and their family caregivers were included, and of the 58 patients invited, 48 (83%) were willing to participate. The ten patients who did not want to participate was due to lack of surplus. The completion rate for the second and the third chemotherapy cycle was 90% and 83%, and the dropout was explained by a lack of surplus, some were hospitalised or the chemotherapy was stopped due to the health issues. This also meant that the patients who finished the study were the patients in the best general condition and tolerated the treatment better. This may also be a possible limitation to the generalisability of the findings, as some of the most vulnerable patients were not included. Only patients receiving palliative chemotherapy were included, but as described the immunotherapy was only about to be implemented to this patient group at inclusion start, and patients receiving radiotherapy had some other cadences in their treatment. It would have been difficult to include both patients undergoing both chemotherapy and radiotherapy due to the constraints of time. It is evident from earlier studies that patients undergoing palliative radiotherapy also have high expectations of a cure [196], but it would have been interesting to include patients' receiving immunotherapy as well, and this may have given an opportunity to strengthened the generalisability of the findings. Sometimes there was not a new patient to include for up to 2-3 weeks, and sometimes the patients we planned to include were in general poor health and could not go onto a course of chemotherapy. They described it as overwhelming, and they did not have the surplus energy to attend while they also should relate to the new treatment they were about to receive. Previous research, has described, patients with palliative needs are a difficult population to include in research [197]. As described by a palliative care researcher: *"The work we do is by nature challenging and will always be. It's hard to do research with such a vulnerable patient population and their families. It's hard to recruit them, it's hard to follow them"* [197]. This together with the small sample size could be a concern when generalising the results in other groups or settings. Collection of data in other hospitals or to broaden the inclusion criteria may have strengthened the generalisability. Yet we believe the study gives a good insight into Danish incurable cancer patients and their family caregivers' expectations and QoL during palliative chemotherapy.

In study 2 an integrative review was carried out, and it was throughout a stringent process, from literature search, data collection to reporting in the paper following the PRISMA guidelines, which strengthen the reliability of the study, as Kvale define the reliability as: *"the consistent and trustworthiness of the results"* [128]. In all stages e.g., beginning with the literature search, we reported the full search strategy including inclusion and exclusion criteria, and all steps were made transparent. This strengthen the reliability and validity of the results, as any other researcher can repeat the literature search and find the same primary articles [193, 198]. Validity are defined by Kvale and also in line with Polit and Becks definition, that inferences made, should be well-founded [128, 193]. However, a limitation is that some studies may be missing, due to the inconsistencies of definitions in current literature about end-of-life discussions, as also described in paper 2. A limitation may also be that the search word "patient" or "family" did not include as part of the search word, we however discussed this with the librarian, providing us with guidance regarding the search strategy, several times. The aim was to conduct current research regarding the nurses' involvement. Therefore, the search words "patient" or "family caregivers" were not used – but we anticipated that by using and combining only the word nurses, end-of-life discussions and incurable cancer, a broad section of research would be localised. However, a further search was carried out once again in CINAHL, by combining the current search with "family caregiver". The search was narrow and came up with only 129 hits, title and abstract were screened, but T.I. did not identify new research articles. In hindsight, interventional studies could have been included. All 3271 articles were screened by two researchers (T.I and K.B.D), which have strengthened the validity of the results, as we continuously discussed any doubts. However, the full text screening was only carried out by T.I, which may be a limitation. In future systematic reviews, it will be beneficial to be two researchers screening this part. Finally, the analysis was also carried out by T.I., and supervised by the research team. A methodological limitation of the study validity is that data was analysed and interpreted by only one researcher, however the analysis has been inspired by the phenomenological hermeneutical approach when analysing the data, and the reporting is carried out in a transparent manner, for example by presenting in paper 2 in a table whereby codes were generated to themes. Furthermore, the analysis process and development of themes were over and over again discussed with supervisors, and also discussed with PhD colleagues when presenting the findings. Kvale and Brinkman talk about generalisation which means that findings can be used in other and similar settings [128]. Even though this integrative systematic review consisted of and included both qualitative and quantitative papers, and included in total n=867 nurses, there is not a tradition for generalising findings in qualitative studies, but the findings of this integrative systematic review are assessed as applicable in similar context.

The aim of study 3 was to gain knowledge of the perspective from both patients, family caregivers and nurses, and thereby subjective descriptions from the participants. The qualitative approach was suitable to investigate the phenomena in focus, which was "end-of-life discussions". By using both participant observations, and by following up with interviews, the validity of the study was strengthened [199]. As described earlier, the overall PhD study was inspired by the systemic theory, but the oncologists did not want to be a part of the study. Some of the observations were carried out in medical conversations where the oncologist also took part, together with the family and nurse. This was a challenge, because how could the patient, family and nurses be observed, in a room, where the oncologist also took part with an overall theoretical frame inspired by the systemic theory? I strived to only observe the patient, family and nurses, but kept in mind that the oncologist appearance also affected the patient, the family and the nurses, just as described in the systematic theory [76]. We do not exactly know the reasons why the oncologist did not wish to be a part of the study, but it could be due to different beliefs about the study, or maybe they did not have enough knowledge of the study and participant observations in general.

In qualitative research the researcher is always a part of the data collection and affects it. This can be a limitation if the role is not made transparent [126]. However, I reflected on my role during the data collection, which was mainly a moderate role, but used a pragmatic approach in the observations. An example of this was when I suddenly experienced being an important person in the patients' course of treatment was when I had met the patient and family three times previously and the nurse who was to give the chemotherapy had never met the patient before. The patient was hoarse, and this was not documented in the medical records, and the patient could not remember the degree of it. The nurse then turned around and asked me if I could remember it, and I could. This invited me to a more active participant as described by Kristiansen & Krogstrup, and Spradley [126, 127]. In these situations, I was aware that my active participation could have an impact on the data. When I felt "accepted" such as in these situations, I suddenly experienced other challenges. I had to be aware that I was not too close to the participants, neither too distanced, as also described by both Krogstrup and Spradley [126, 127]. An example was when a family invited me to be a part of the medical consultation and sit together with the family during the consultation. I usually sat at the back of the room, and the patients and family suddenly felt I was a very important piece of their treatment, with some important information and needed me to join the conversation. They told me it was good and comforting knowing that I would be there every single time they went to visit the outpatient clinic. Continually I reflected on the consequence of my actions and the benefit I would gain for the research process, also with regard to the system theory that guided this study, where it is described that all family members, and all sub-systems affect each other [76]. Throughout the data collection a note book was used to write down such notes, reflections, and considerations and by giving detailed descriptions of the whole process of data collection including some reflections of difficult and challenging situations, these have strengthened the reliability of the research process [128]. When preparing the interviews an interview guide was developed, which is also a strength to the reliability according Kvale [128]. As described earlier, the transcription was carried out by T.I., even though many researchers delegate the tasks to others [128]. It was important to me, because it made me aware of my own interview style, and I improved my interviews skills when listening to the interviews repeatedly. However, according to Kvale, it could have been beneficial that the transcriptions were made by to researches two ensure reliability when transcribing, and afterwards comparing the transcript [128]. The analysis approach inspired by Paul Ricoeur seemed to be a suitable method. However, one limit may be the large amount of data that was generated in the study. The analysis process was challenging, and it was also difficult to combine all three perspectives in one paper. It may have been affected the findings in the way that we could have gained more in-depth knowledge if we would have chosen only one perspective. I also reflected on how I used my preconceptions to be more reactive and thereby make it transparent how the findings derived. Validation of the data analysis also consisted of continually discussion with my supervisors, but also PhD colleagues, but also by presenting the findings to others. For example, findings were presented on a PhD course "Introduction to qualitative research" at Aarhus University, which provided the opportunity to discuss the findings with fellow PhD students from other professions and universities. This also increased validity. By discussing and interpreting the findings with theory, this gave some new insight and a new understanding of the topic, but these findings could be interpreted differently by any other researcher and theory. By documenting and describing all steps of the research process, it is possible to use the findings in other and similar situations, but according to Kvale the findings cannot be generalised due to the small number of participants [128]. Finally, the oncologists did not want to be a part of the PhD study, as we had hoped for when planning the three sub-studies. This would have been beneficial to include the oncologist as well and follow their involvement in end-of-life discussions as well. Palliative care is an inter-professional approach, and this is a limitation to the study that we only included patient, family caregivers and nurses, as the oncologist also can be assumed as having a large part in end-of-life discussions and especially in treatment discussions.

Conclusion

The overall aim of this PhD study was to gain knowledge about expectations, QoL and end-of-life discussions in patients diagnosed with incurable thoracic cancer during their course with palliative chemotherapy. The PhD study included the perspective of both patients, family caregivers and nurses and combined both quantitative and qualitative approaches.

We have gained knowledge on patients and family caregivers expectations to palliative chemotherapy and patients QoL. We found that a higher percentage of the younger patients expected a cure than the older patients. Furthermore, it was found that patients and family caregivers had different treatment expectations. Patients overall QoL decreased throughout the course of palliative chemotherapy, but there was no difference between the age groups.

Regarding knowledge of end-of-life discussions we gained new knowledge. The nurses have some well-defined roles in end-of-life discussions with patients and their family caregivers, both also have some undefined tasks – for example in medical consultations and they were unsure of who had the responsibility for initiating the end-of-life discussions. We also found that the nurses' experienced they had insufficient competences to initiate and engage in the discussions, and they also experienced that it could be a challenge to involve the families. End-of-life discussions with patient and their family caregivers were in this PhD study seldom initiated in clinical practice, which may be due to the physical environment, lack of continuity among nurses, and nurses' instrumental task workloads. This PhD study has shed light on especially the nurses' involvement in end-of-life discussions, but the inter-professional collaboration is essential for providing palliative care. There may be a need to find other ways to organise and structure palliative care in busy outpatient clinics, here among end-of-life discussions and family involvement. Furthermore, changes in palliative care education in undergraduate and postgraduate level may be important.

Implications for practice

From this PhD study, there are different implications important to utilise to improve current practice regarding palliative care, here among end-of-life discussions and family involvement in outpatient oncology clinics. Below implications will be elaborated on three levels:

1) Structural level
2) Educational level
3) Individual level

Structural level

This study implies that the leaders may act and find new structures that underpin the opportunity to provide palliative care focusing systematically on assessment of treatment expectations, QoL and family involvement in end-of-life discussions. For example, there may be a need for appropriate rooms, more time and continuity among the health care professions if palliative care in outpatient clinics should succeed. Furthermore, all patients and families on a course of palliative chemotherapy may benefit from may being systematically invited to attend an end-of-life discussions.

Another consideration is that the general palliative care level may benefit from adapting inter-professional conferences as carried out in the specialised palliative care where complex patient cases are discussed. Palliative care and end-of-life discussions should be carried out as a partnership where nurses, physicians and other important professionals work together instead of beside each other.

Educational level

This study implicates that it may be important to build up cultures that integrate and work with palliative care, end-of-life discussions and family involvement in their daily practice. This may be achieved by teaching and focusing on palliative care early in their career, already in basic educations. Education in palliative care at undergraduate and postgraduate level may be beneficial for the palliative care provided to patients and their families and may promote and contribute to an inter-professional culture. Key figures in all outpatient oncology clinics could be important to improve such a culture.

Furthermore, it seems necessary that all newly educated, and newly employed health care professionals build up clinical competences in palliative care and family involvement. This could be done by education in basic concepts and theories, but also professional guidance in clinical practice, by for example the specialised palliative care team, experiences colleagues, or key figures.

Individual level

A possible move forward is that health care professionals initiate discussions of treatment expectations and QoL, as it is the starting point for other decisions throughout the course of disease. Furthermore, there should be focus on the potential difference in treatment expectations between age groups in the discussions.

It may be important that all health care professionals involved in the patients disease, discuss their own and each other roles in end-of-life discussions and also who is responsible before they are carried out. But also establish a clear role clarification within the organisation, so everybody knows their specific task is for example the physician and nurse have related to palliative care and end-of-life discussions. This may ensure that discussions are carried out and not carried out too late. Health care professionals must reflect on their own values regarding palliative care, as it is known that health care professionals advocating for palliative care are beneficial for the integration of palliative care.

A last consideration is that health care professionals should be aware that end-of-life discussions must be individualised, as the patients and family caregivers have different wishes for conversations.

Future research

The current PhD study have contributed to existing knowledge regarding treatment expectations, QoL and end-of-life discussions in outpatient oncology settings. As this PhD study was mainly explorative, there are two main areas that would be important to focus on in future research.

There is a clear need for more research in palliative care at the generalist palliative care level. It would be interesting to investigate how changes in structures in the outpatient oncology clinics could affect the care provided to patients and families, but this may also be beneficial for the nurses and other health care professionals. For example, there is a need to investigate if more education in palliative care and end-of-life discussion, time to end-of-life discussions and continuity could be beneficial for both patients, families, nurses and other health care professionals providing care in outpatient oncology clinics.

There may be a lack of mandatory training in palliative care in undergraduate and postgraduate levels. A formalised generic educational program for nurses, and other health care professionals, in outpatient oncology clinics should be developed, with the aim to gain knowledge on the concept of palliative care, how to engage in end-of-life discussions, and how to involve families.

The families should be included in future the interventional studies, as there is lack of interventions that includes the families in end-of-life discussions [200, 201]. It could be interesting to plan an intervention that consisted of systematically invitations to patient and their family to attend an end-of-life discussion.

The end-of-life discussions should focus on patients QoL, treatment expectations of all family caregivers, and discussions of wishes for treatment, how the patients and families wish to prioritise the remaining time of life, and the future care. This discussion should take its starting point from patients and families individual wishes. The discussion could be offered after disease progression.

Even though the PhD study didn't found any significantly difference in treatment expectations, a higher percentage of the younger patients expected a cure compared to the older patients. This call for more attention to potential difference in treatment expectations among age groups, and future studies should investigate this further. By including more participants in future studies, this would give an opportunity to strengthen the findings in this PhD study. By this, I believe we would come a step closer to an improvement of palliative care in outpatient oncology clinics.

English summary

Background

This PhD study was carried out during my employment at the Department of Oncology at Odense University Hospital, Denmark, and the University of Southern Denmark between 2018-2021.

Many patients with incurable thoracic cancer (mentioned in this PhD study as non-small cell lung cancer, small-cell lung cancer and mesothelioma) are receiving palliative chemotherapy. When making treatment decisions, expectations related to the treatment and the patients' quality of life there are important factors to discuss, as they are crucial for other decisions in the course of disease, for instance decisions related to the disease, wishes for the future care, or how to priorities the rest of their life. However, there is a lack of knowledge on Danish patients' expectations and quality of life and if age has an impact, and also a lack of knowledge of the family caregivers' expectations. Discussions of treatment expectations, quality of life and other decisions related to the course of disease may be carried out in an end-of-life discussion. An end-of-life discussion is in this PhD thesis defined as a conversation between a patient, family caregiver and a nurse. Research has shown that patients and family caregivers wish to take part in such discussions, but in Denmark there is not systematic approach to such conversations. The nurse has an important and essential role during palliative treatment, together with the inter-professional team, because he/she is the one spending the most time with patients, and thereby could initiate and facilitate such discussions. However, in International and Danish context there is a lack of knowledge of nurses' involvement in an oncology outpatient setting.

Aim

The aim of the PhD study was to investigate the treatment expectations, quality of life and end-of-life discussions in a course of palliative chemotherapy. The PhD study included perspectives of both patients, family caregivers and nurses.

Methods and results

Three different methodological approaches were used to investigate the aim:

Study 1: A prospective longitudinal survey study. Patients were asked three times during palliative treatment to provide a survey on treatment expectations and on quality of life, using the Functional Assessment of Cancer Therapy – General questionnaire. The family caregivers' treatment expectations were assessed once. Analysis was carried out with descriptive statistic, students' t-test and ANOVA.

We included 48 patients and 36 family caregivers. No statistically significant differences between the age groups in treatment expectations and quality of life was found. In patients <70 years 28% expected a cure, whilst 7% of patients ≥70 years and 36% of family caregivers expected a cure. In both age groups quality of life significantly decreased during palliative chemotherapy (p=0.02). In subgroup analysis, no significant difference between the age groups was demonstrated.

We included 15 eligible articles: Qualitative (n=12) and quantitative (n=3). The data analysis resulted in four overall themes: 1) Nursing roles; the advocating, supporting and reframing roles, and an undefined task e.g., in medical consultations 2) Trust building 3) Nurse competences 4) Medical issues. The nurse has several roles in end-of-life discussions, but insufficient competencies to be involved in that kind of discussions, e.g., to involve and communicate with families.

We included 9 patients, 8 family caregivers, and 11 nurses. Three themes were identified 1) Content in end-of-life discussion 2) Timing of end-of-life discussion 3) Challenges in end-of-life discussions. End-of-life discussions were seldom initiated; when they were, it was often too late. Discussions addressed treatment, place of care, practical/economic concerns, and existential matters. The physical environment at the outpatient clinic, lack of continuity, and nurses' instrumental task workloads and time pressure posed challenges to initiating end-of-life discussions.

Conclusion

In conclusion, patient and family caregivers had high treatment expectations. There were no differences in QoL in patients <70 years and ≥70 years. The nurses had many roles in end-of-life discussions but insufficient competencies to engage in them. End-of-life discussions were seldom initiated in practice, and when they were initiated, it was often too late. Physical environment, lack of continuity, and nurses work load, and time pressure were barriers for initiating and carry out end-of-life discussions.

Implication for practice

This knowledge is especially valuable for nurses and other healthcare professionals providing general palliative care in hospital settings. Nurses must proactively invite patients and family caregivers to attend end-of-life discussions, and this should be offered several times, ensuring that they take place in a timely way. They should preserve discussions of treatment expectations and quality of life, as they are important factors that affects other decisions during treatment. End-of-life discussions should be individualised and patients and family caregivers must decide on the content and appropriate time for them. The findings also implicate an educational need among the nurses and point towards an organisational change in the outpatient clinics, e.g., that end-of-life discussions follow a more structured approach and are offered in a scheduled manner. Furthermore, the PhD study implicates that education in palliative care, end-of-life discussions, and family involvement on both undergraduate and postgraduate are important to utilize in order to improve the care provided to patients with incurable cancer and their families.

Danish summary

Dette ph.d.-studie er gennemført under min ansættelse på Onkologisk Afdeling på Odense Universitetshospital og Syddansk Universitet mellem 2018-2021. Mange patienter med uhelbredelig lungekræft (i denne ph.d. nævnt som ikke småcellet lungekræft, småcellet lungekræft og mesoteliom) diagnosticeres med uhelbredelig sygdom allerede ved diagnosetidspunktet, og indgår i et pallierende forløb med kemoterapi. Forskning har vist, at patienter der modtager pallierende kemoterapi, har høje forventninger til at blive helbredt, men der mangler viden om danske patienter med lungekræft og pårørendes forventninger, og om alder har betydning. Forventninger er vigtige at få afstemt, da de er afgørende for hvorledes beslutninger relateret til sygdom, behandling og fremtiden bliver taget. I et forløb med pallierende forløb, er livskvalitet et vigtigt endepunkt for at kunne tage beslutninger om behandling og det videre forløb. International forskning viser, at patienter med lungekræft i et forløb med pallierende kemoterapi har stabil livskvalitet gennem forløbet. Kun få internationale studier har sat fokus på alders betydning for livskvaliteten og det er vigtigt at få viden om ift. de beslutninger der tages omkring behandling og andre beslutninger i forløbet. Ifølge Sundhedsstyrelsen i Danmark, er det vigtigt at forholde sig til beslutninger relateret til fx sygdom, behandling og fremtiden. Dette kan gøres for eksempel vha. en samtale mellem patient, pårørende og sundhedsprofessionelle, hvor ønsker for behandling og for fremtiden diskuteres. Tidligere forskning har vist at patienter og pårørende gerne vil indgå i disse samtaler, og de har gavn af dette, men der er ikke nogen systematisk praksis i Danmark for at afholde samtaler som disse. Sygeplejersken har sammen med resten af det tværfaglige team en vigtig rolle ift. at tale med patient og familie om fremtidige ønsker, og har en stor mulighed for at initiere og facilitere samtalerne. I en international og dansk onkologisk kontekst ved vi endnu ikke meget om sygeplejerskens involvering i disse beslutninger.

Formål

Formålet var, at få viden om forventninger, livskvalitet og involvering i samtaler om beslutninger ved livets afslutning i et forløb med uhelbredelig lungekræft. Afhandlingen inkluderer både patienter, pårørendes samt sygeplejerskers perspektiver. Ovenstående formål er undersøgt gennem tre forskellige metodologier.

Metode og resultater

Formålet blev undersøgt ved tre metodologiske tilgange.

Studie 1: Et prospektivt longitudinelt studie. Patienterne blev fuldt tre gange gennem deres behandling med pallierende kemoterapi, of fik udleveret et spørgeskema med spørgsmål om behandlingsforventninger og livskvalitet, spørgeskemaet: Functional Assessment of Cancer Therapy –

General questionnaire blev anvendt. Familiemedlemmernes behandlingsforventninger blev vurderet en gang. Analysen blev udført med deskriptiv statistik, t-test og ANOVA-analyse.

I alt blev 48 patienter og 36 pårørende inkluderet. Der blev ikke fundet nogen statistisk signifikans forskel mellem aldersgrupperne i behandlingsforventninger eller livskvalitet. For patienter

<70 år forventede 8% at blive helbredt, mens patienter ≥70 år var 7% der forventede at blive helbredt. Ved familierene var der 36% der forventede helbredelse. Samlet i aldersgrupperne faldt livskvaliteten signifikant gennem forløbet med lindrende kemoterapi (p=0.02).

Studie 2: En systematisk litteratur gennemgang, som blev udført jævnfør PRISMA guidelines. PROSPERO registreringsnummer: CRD42020186204. Både CINAHL, Medline, PsycInfo, Embase blev gennemsøgt for relevant litteratur. Dataanalysen blev udført med inspiration fra Whittemore and Knafls tilgang.

I alt inkluderede vi 15 artikler, 12 kvalitative, og 3 kvantitative. Analysen resulterede i fire overordnede temaer: 1) Sygeplejerskens rolle, 2) at opbygge tillid, 3) sygeplejerske kompetencer, 4) medicinske udfordringer. Sygeplejersken havde mange roller i samtalerne, men oplevede ikke at have tilstrækkelig med kompetencer til at indgå i disse, for eksempler ift. at kommunikere med familien.

Studie 3: Et fænomenologisk hermeneutisk studie. Data blev indsamlet vha. deltager observationer, uformelle og semi-strukturerede eller familie interview med patienter og familier, og fokusgrupper blev udført med sygeplejerskerne. Til at analysere data blev der anvendt en Ricoeur inspireret metode.

Det fænomenologiske hermeneutiske studie inkluderede i alt 9 patienter, 8 pårørende og 11 sygeplejersker. Analysen resulterede i tre temaer: 1) indhold i samtaler om beslutninger ved livets afslutning, 2) tidspunkt for samtaler om beslutninger ved livets afslutning, 3) udfordringer i samtaler om beslutninger ved livets afslutning. Samtalerne blev sjældent initieret i praksis, og når de blev initieret, var det ofte for sent. Samtalerne handlede om behandling, sted for pleje i den sidste tid, praktiske og økonomiske bekymringer og eksistentielle problemer. De fysiske omgivelser i ambulatoriet, mangel på kontinuitet og det, at sygeplejerskerne havde mange opgaver og var under tidspres, gjorde at det var en udfordring for dem at initiere samtalerne.

Konklusion

Vi konkluderer at patienter og pårørende har høje forventninger til at blive helbredt at pallierende kemoterapi, samtidig var der ingen forskel på livskvalitet og behandlingsforventniner mellem patienterne <70 år og ≥70 år. mange roller i samtaler om beslutninger ved livets afslutning, men manglende kompetence til at indgå i dem. Vi kan også konkludere at samtaler om beslutninger ved livets afslutning sjældent bliver initieret i praksis, og ofte for sent. Fysiske omgivelser i ambulatoriet, mangel på kontinuitet og det, at sygeplejerskerne havde mange opgaver og var under tidspres, gjorde at det var en udfordring for dem at initiere samtalerne.

Implikationer for praksis

Denne viden er specielt vigtig for sygeplejersker og andre sundhedsprofessionelle der arbejder med basal palliation i ambulatorier. Sygeplejersker må proaktivt invitere patient og familier til at deltage i samtaler, og dette må tilbydes flere gange gennem forløbet for at sikre at samtalerne udføres ifølge deres behov. Samtalerne må indeholde emner som forventninger til behandling og livskvalitet, fordi det er vigtige emner for at kunne tage andre beslutninger om hvad patienterne ønsker for fremtiden. Samtalerne må individualiseres og patient og familie skal være med til at beslutte hvad der er vigtigt for dem at tale om. Fundende peger også mod et uddannelsesmæssigt behov for sygeplejerskerne, men også et behov for strukturændringer i ambulatorierne. For eksempel at samtalerne bliver mere strukturerede og måske endda skemalagt. Derudover kan uddannelse om palliation, samtaler om beslutninger ved livets afslutning, og familie involvering allerede på basisuddannelser, men også hos sundhedsprofessionelle være vigtigt for at forbedre forløbet hos patienter med uhelbredelig kræft og deres familier.

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Appendices

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Appendix 1 - Preconceptions

Before starting my PhD I had a bachelor in nursing and formerly employed on a palliative unit, I have an overall insight in the challenges patients and families with an incurable cancer diagnosis undergo.

I have had many conversations with patients and their families about end-of-life care, and helped them to decide when a life-prolonging treatment (fluid therapy, antibiotics etc.) had to be stopped. I will consider myself as experienced in talking to patients about end-of-life wishes. There talks were mostly initiated by the bedside and not in an outpatient setting – I often experienced this talks took place too late in the palliative course. I have several times experienced that the cancer was neglected by the families, and once I experienced a wife begging me to tell it was not true that her husband was dying. This was also one of my biggest motivations when going in to this PhD. We must do something.
After my master thesis, I worked in an endoscopy section. I have been involved in endoscopic ultrasound procedures where cancer of the pancreas were diagnosed. I have also performed pre- and post-operative care for this patient group in a surgical ward.

In addition, my master thesis addressed the needs and challenges of families to patients diagnosed pancreatic cancer patients by interviewing the families.
However, I have not cared for people diagnosed with lung cancer. I have not worked as an oncological nurse and I have never given chemotherapy. Therefore, I am not familiar with the culture and the nurses' workflow at the Department of Oncology. This could be an advantage because I am able to access the field with new eyes and because I am not familiar with the situation of the families. In contrast, it can also be a disadvantage because I may be blind to some of the things that are going on in the course of treatment.

Appendix 2 - Participant information to patients – study 1

Deltagerinformation

Du skal i kræftbehandling, og i den forbindelse vil vi spørge, om du vil deltage i et forskningsprojekt.

Formålet med projektet er at undersøge, hvordan din livskvalitet er i perioden, hvor du modtager kræftbehandling. Samtidig ønsker vi, at få mere viden om hvilke forventninger du har til de forestående behandlinger, og om disse ændres undervejs. Derfor beder vi dig udfylde et spørgeskema ved din første og anden behandling og igen før den opfølgende samtale, når behandlingsforløbet er afsluttet. Spørgeskemaerne kan evt. udføres som telefoninterview, efter aftale.

Resultaterne vil blive udgivet i videnskabelige tidsskrifter. Hverken dit navn eller andre informationer, der kan identificere dig, vil være tilgængelige for samarbejdspartnere eller blive udgivet i publikationer eller rapporter.

Erklæring fra deltager

Jeg giver hermed samtykke til at deltage i forskningsprojektet, og tilladelse til at de projektansvarlige får adgang til min patientjournal med henblik på oplysninger om undersøgelser, kræftdiagnose og min kræftbehandling. Alle oplysninger vil blive behandlet fortroligt, og vil blive anonymiseret og opbevaret på Odense Universitetshospital under samme sikkerhedsforhold, som gælder min patientjournal.

Jeg har fået skriftlig og mundtlig information, og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage. Jeg ved, at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage, uden at det får indflydelse på min nuværende eller fremtidige rettigheder til behandling.

Deltagers navn: ____

Dato: ____________ **Underskrift:** ____________________________________

Du er velkommen til at kontakte mig, hvis du vil høre mere om projektet.

Med venlig hilsen

Tine Ikander (projektansvarlig)
Sygeplejerske og ph.d. studerende
Tlf: + 45 29 64 86 37
Mail: tine.moller.ikander@rsyd.dk

Appendix 3 - Participant information to family caregivers – study 1

Deltagerinformation

Du er pårørende til en patient, som skal i kræftbehandling, og i den forbindelse vil vi høre om du vil deltage i et forskningsprojekt. Formålet med projektet er at undersøge, hvilke forventninger du som pårørende har til den forestående behandling. Derfor beder vi dig om at udfylde et kort spørgeskema.

Erklæring fra deltager

Jeg giver samtykke til at deltage i forskningsprojektet, og jeg har fået skriftlig og mundtlig information, og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage. Jeg ved, at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage, uden at det får konsekvenser for behandlingen. Alle oplysninger vil blive behandlet fortroligt, og vil blive anonymiseret og opbevaret på Odense
Universitetshospital.

Deltagers navn: ____

Dato: ____________ **Underskrift:** ______________________________________

Du er velkommen til at kontakte os, hvis du vil høre mere om projektet.

Med venlig hilsen

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Appendix 4 - Survey handed out to patients – study 1

Bor du alene eller sammen med andre? *(Sæt kun ét kryds)*	☐ Bor med ægtefælle/samlever og evt. børn ☐ Bor alene med børn (hele tiden eller noget af tiden) ☐ Bor alene Andet: ______________________
Hvordan er du uddannet? *(Sæt kun ét kryds)*	☐ Under 10 års skolegang (folkeskole) ☐ Ungdomsuddannelse (fx gymnasium og/eller håndværksuddannelse) ☐ Mellemlang videregående uddannelse (fx lærer, skuespiller, diplomingeniør) ☐ Lang videregående uddannelse (universitetsuddannelse, fx læge eller advokat)
Beskæftigelsessituation (før du blev syg)	☐ I arbejde ☐ Uden for arbejdsmarkedet
Har du, eller har du haft længerevarende sygdom(me) samtidig med din kræftsygdom?	☐ Nej, jeg har ikke haft andre længerevarende sygdomme samtidig med min kræftsygdom ☐ Ja Hvilke? ______________________

Spørgeskema om livskvalitet

Nedenfor er anført en række udsagn, som andre mennesker med din sygdom har sagt, er vigtige.
Ved at sætte en ring omkring eller markere ét tal i hver linje bedes du angive dit svar, sådan at det passer på de seneste 7 dage.

	FYSISK VELBEFINDENDE	**Slet ikke**	**En lille smule**	**I nogen grad**	**En hel del**	**Meget**
GP1	Jeg mangler energi	0	1	2	3	4
GP2	Jeg har kvalme	0	1	2	3	4
GP3	På grund af min fysiske tilstand har jeg svært ved at opfylde min families/mine nærmestes behov	0	1	2	3	4
GP4	Jeg har smerter	0	1	2	3	4
GP5	Jeg er generet af bivirkninger af behandlingen	0	1	2	3	4
GP6	Jeg føler mig syg	0	1	2	3	4
GP7	Jeg er tvunget til at være sengeliggende noget af tiden	0	1	2	3	4

	SOCIALT/FAMILIEMÆSSIGT VELBEFINDENDE	**Slet ikke**	**En lille smule**	**I nogen grad**	**En hel del**	**Meget**
GS1	Jeg føler mig tæt knyttet til mine venner	0	1	2	3	4
GS2	Jeg får følelsesmæssig støtte fra min familie/mine nærmeste	0	1	2	3	4
GS3	Jeg får støtte fra mine venner	0	1	2	3	4
GS4	Min familie/mine nærmeste har accepteret min sygdom	0	1	2	3	4
GS5	Jeg er tilfreds med den måde, vi taler om sygdommen på i familien/blandt mine nærmeste	0	1	2	3	4
GS6	Jeg føler mig tæt knyttet til min partner (eller den person, der er min bedste støtte) der er min vigtigste støtte)	0	1	2	3	4
Q1	Uanset om du er seksuelt aktiv eller ej, bedes du venligst besvare følgende spørgsmål - Hvis du ikke har lyst til at besvare spørgsmålet, bedes du sætte kryds i boksen og gå videre til næste udsagn.	☐				
GS7	Jeg er tilfreds med mit sexliv	0	1	2	3	4

	FØLELSESMÆSSIGT VELBEFINDENDE	Slet ikke	En lille smule	I nogen grad	En hel del	Meget
GE1	Jeg er ked af det	0	1	2	3	4
GE2	Jeg er tilfreds med den måde, jeg klarer min sygdom på	0	1	2	3	4
GE3	Jeg er ved at give op i kampen mod min sygdom 0	0	1	2	3	4
GE4	Jeg føler mig nervøs	0	1	2	3	4
GE5	Jeg er bekymret for at dø	0	1	2	3	4
GE6	Jeg er bekymret for, at min tilstand vil forværres 0	0	1	2	3	4

	FUNKTIONELT VELBEFINDENDE	Slet ikke	En lille smule	I nogen grad	En hel del	Meget
GF1	Jeg er i stand til at arbejde (inkluderer arbejde i hjemmet)	0	1	2	3	4
GF2	Mit arbejde (inkluderer arbejde i hjemmet) er tilfredsstillende	0	1	2	3	4
GF3	Jeg er i stand til at nyde livet	0	1	2	3	4
GF4	Jeg har accepteret min sygdom	0	1	2	3	4
GF5	Jeg sover godt	0	1	2	3	4
GF6	Jeg nyder det, jeg plejer at lave for min fornøjelses skyld	0	1	2	3	4
GF7	Lige nu er jeg tilfreds med min livskvalitet	0	1	2	3	4

Dine forventninger til kræftbehandlingen

Efter du har snakket med din læge om kræftbehandlingen, hvilke er dine primære forventninger til den behandling du skal have i dag? *(Sæt gerne flere krydser)*			
Lindring af ubehag eller smerter	☐	**Vinde levetid**	☐
Helbredelse	☐	**Ved ikke**	☐

Appendix 5 - Survey handed out to family caregivers – study 1

Navn ____________________

Alder ____________________

Relation ____________________

Hvilke er dine primære forventninger til den kræftbehandling, som din pårørende skal modtage? *(Sæt gerne flere krydser)*			
Lindring af ubehag eller smerter	☐	**Vinde levetid**	☐
Helbredelse	☐	**Ved ikke**	☐

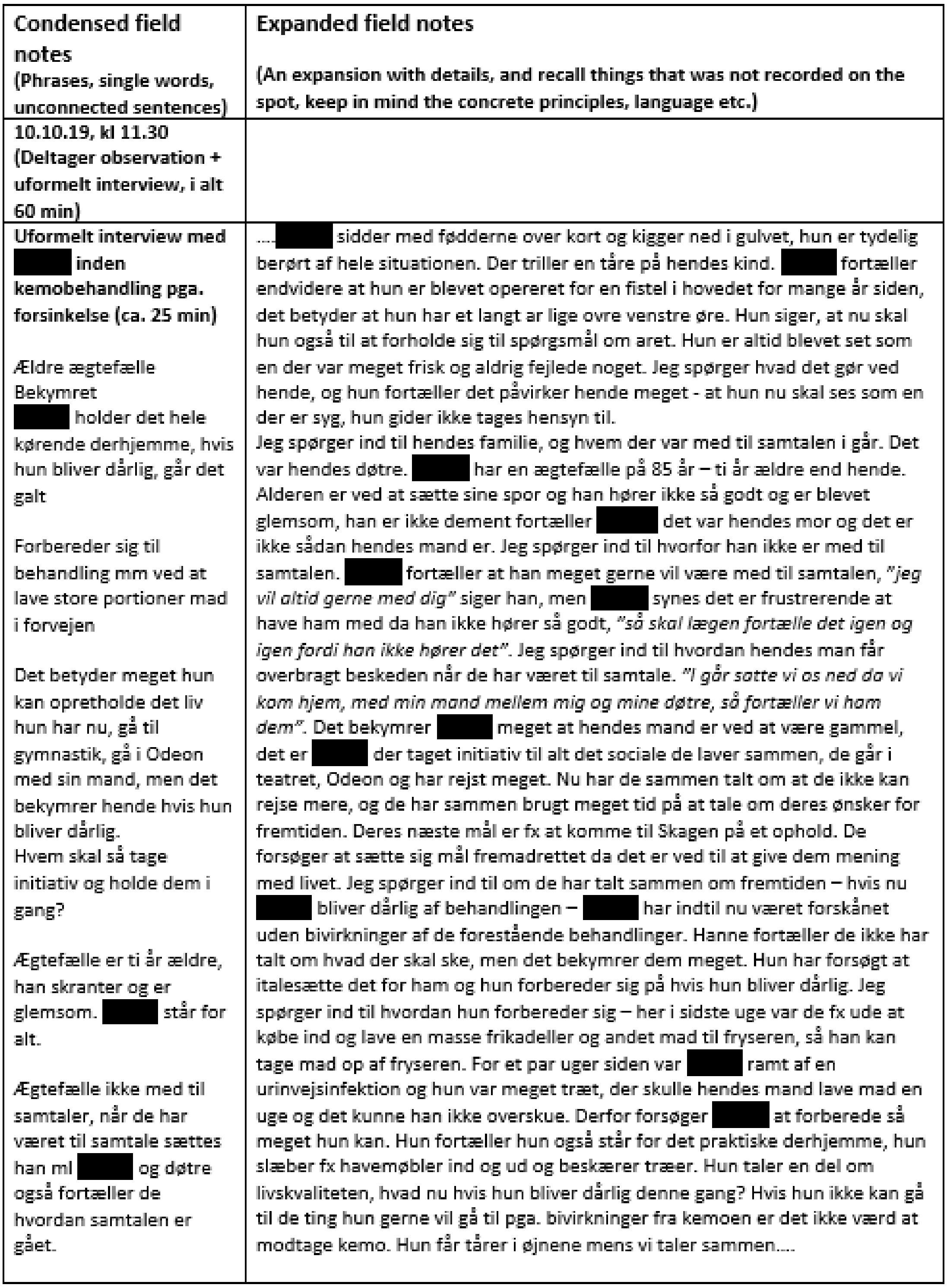
Appendix 6 - Detailed results of quality appraisal – study 2

Author/ year	Article	Title/ abstract	Introduction/ aim	Method /data	Sampling	Data analysis	Ethics	Bias	Results	Transferability /generalisability	Implications/usefulness	Total score
Broom et al. 2015	Negotiating Futility, Managing Emotions: Nursing the Transition to Palliative Care	3	4	3	3	4	4	2	4	3	4	<u>34</u>
Broom et al. 2016	Nursing futility, managing medicine: Nurses' perspectives on the transition from life-prolonging to palliative care	3	4	3	3	4	4	2	4	4	2	<u>33</u>
Laryionava et al. 2018	"Rather one more chemo than one less…": Oncologists and Oncology Nurses' Reasons for Aggressive Treatment of Young Adults with Advanced Cancer	3	3	3	4	2	2	1	4	4	4	<u>30</u>
McLennon et al. 2013	Oncology nurses' experiences with prognosis-related communication with patients who have advanced cancer	4	4	4	4	4	2	1	4	4	2	<u>33</u>
McLennon et al.	Oncology Nurses' Narratives About Ethical	4	4	3	4	4	3	1	4	4	3	<u>34</u>

2013	Dilemmas and Prognosis-Related Communication in Advanced Cancer Patients											
McCollough et al. 2010	A model of treatment decision making when patients have advanced cancer: how do cancer treatment doctors and nurses contribute to the process?	3	3	3	3	2	4	1	4	3	3	29
Mohammed et al. 2020	"I'm going to push this door open. You can close it": A qualitative study of the brokering work of oncology clinic nurses in introducing early palliative care	4	4	4	3	4	3	2	4	4	3	35
Pettersson et al. 2018	Ethical competence in DNR decisions -a qualitative study of Swedish physicians and nurses working in hematology and oncology care	4	3	4	3	4	4	3	4	3	4	36
Pettersson et al. 2014	Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care	4	4	4	4	3	4	3	4	4	3	37
Rylander et al. 2019	Significant aspects of nursing within the process of end-of-life communication in an oncological context	4	3	3	3	4	4	1	4	3	3	32

Tariman et al. 2016	Oncology Nursing and Shared Decision Making for Cancer Treatment	3	3	3	3	3	1	1	2	2	3	24
Valente et al. 2011	Nurses' perspectives of challenges in end of life care	2	2	3	2	3	2	1	2	3	2	22
Blazeviciene et al. 2017	Oncology nurses' perceptions of obstacles and role at the end-of-life care: cross sectional survey	3	4	4	3	4	4	3	4	3	3	36
Boyd et al. 2011	Nurses' Perceptions and Experiences With End-of-Life Communication and Care	3	3	3	3	3	1	1	3	3	4	27
De Angst et al. 2019	Should we involve patients more actively? Perspectives of the multidisciplinary team on shared decision-making for older patients with metastatic castration-resistant prostate cancer	4	3	4	3	4	4	1	4	3	3	33

Appendix 7 – Example of fieldnotes



Condensed field notes **(Phrases, single words, unconnected sentences)**	**Expanded field notes** **(An expansion with details, and recall things that was not recorded on the spot, keep in mind the concrete principles, language etc.)**
10.10.19, kl 11.30 (Deltager observation + uformelt interview, i alt 60 min)	
Uformelt interview med [redacted] inden kemobehandling pga. forsinkelse (ca. 25 min) Ældre ægtefælle Bekymret [redacted] holder det hele kørende derhjemme, hvis hun bliver dårlig, går det galt Forbereder sig til behandling mm ved at lave store portioner mad i forvejen Det betyder meget hun kan opretholde det liv hun har nu, gå til gymnastik, gå i Odeon med sin mand, men det bekymrer hende hvis hun bliver dårlig. Hvem skal så tage initiativ og holde dem i gang? Ægtefælle er ti år ældre, han skranter og er glemsom. [redacted] står for alt. Ægtefælle ikke med til samtaler, når de har været til samtale sættes han ml [redacted] og døtre også fortæller de hvordan samtalen er gået.	....[redacted] sidder med fødderne over kort og kigger ned i gulvet, hun er tydelig berørt af hele situationen. Der triller en tåre på hendes kind. [redacted] fortæller endvidere at hun er blevet opereret for en fistel i hovedet for mange år siden, det betyder at hun har et langt ar lige ovre venstre øre. Hun siger, at nu skal hun også til at forholde sig til spørgsmål om aret. Hun er altid blevet set som en der var meget frisk og aldrig fejlede noget. Jeg spørger hvad det gør ved hende, og hun fortæller det påvirker hende meget - at hun nu skal ses som en der er syg, hun gider ikke tages hensyn til. Jeg spørger ind til hendes familie, og hvem der var med til samtalen i går. Det var hendes døtre. [redacted] har en ægtefælle på 85 år – ti år ældre end hende. Alderen er ved at sætte sine spor og han hører ikke så godt og er blevet glemsom, han er ikke dement fortæller [redacted] det var hendes mor og det er ikke sådan hendes mand er. Jeg spørger ind til hvorfor han ikke er med til samtalen. [redacted] fortæller at han meget gerne vil være med til samtalen, *"jeg vil altid gerne med dig"* siger han, men [redacted] synes det er frustrerende at have ham med da han ikke hører så godt, *"så skal lægen fortælle det igen og igen fordi han ikke hører det"*. Jeg spørger ind til hvordan hendes man får overbragt beskeden når de har været til samtale. *"I går satte vi os ned da vi kom hjem, med min mand mellem mig og mine døtre, så fortæller vi ham dem"*. Det bekymrer [redacted] meget at hendes mand er ved at være gammel, det er [redacted] der taget initiativ til alt det sociale de laver sammen, de går i teatret, Odeon og har rejst meget. Nu har de sammen talt om at de ikke kan rejse mere, og de har sammen brugt meget tid på at tale om deres ønsker for fremtiden. Deres næste mål er fx at komme til Skagen på et ophold. De forsøger at sætte sig mål fremadrettet da det er ved til at give dem mening med livet. Jeg spørger ind til om de har talt sammen om fremtiden – hvis nu [redacted] bliver dårlig af behandlingen – [redacted] har indtil nu været forskånet uden bivirkninger af de forestående behandlinger. Hanne fortæller de ikke har talt om hvad der skal ske, men det bekymrer dem meget. Hun har forsøgt at italesætte det for ham og hun forbereder sig på hvis hun bliver dårlig. Jeg spørger ind til hvordan hun forbereder sig – her i sidste uge var de fx ude at købe ind og lave en masse frikadeller og andet mad til fryseren, så han kan tage mad op af fryseren. For et par uger siden var [redacted] ramt af en urinvejsinfektion og hun var meget træt, der skulle hendes mand lave mad en uge og det kunne han ikke overskue. Derfor forsøger [redacted] at forberede så meget hun kan. Hun fortæller hun også står for det praktiske derhjemme, hun slæber fx havemøbler ind og ud og beskærer træer. Hun taler en del om livskvaliteten, hvad nu hvis hun bliver dårlig denne gang? Hvis hun ikke kan gå til de ting hun gerne vil gå til pga. bivirkninger fra kemoen er det ikke værd at modtage kemo. Hun får tårer i øjnene mens vi taler sammen....

Appendix 8 - Interview guide individual/joint interviews – study 3

Semistruktureret interviewguide til patient og/eller pårørende (Inspireret af Kvale og Brinkman)	
	Navn, alder, diagnose, linje kemoterapi, uddannelse, arbejde, familiemedlemmer/nære pårørende
Indledende spørgsmål Fokuserede spørgsmål	**Tema: Sygdomsforløb og livet med kemoterapi** Kan du/I beskrive jeres hverdag efter du/din pårørende er begyndt at modtage kemoterapi? Kan du/I sætte ord på de oplevelser i har haft i forbindelse med at modtage kemoterapi i ambulatoriet? Hvad taler du/I med sygeplejersken om når/I er inde og modtage behandling? Supplerende: Hvilken betydning har det for jeres hverdag? Hvordan har hverdagen ændret sig? **Tema: Samtaler om beslutninger i forløbet** Kan du fortælle om de forskellige beslutninger I har taget gennem forløbet med kemoterapi? Hvordan taler I om sygdommen og beslutninger relateret hertil indbyrdes i familien? Har I talt med en læge eller sygeplejerske om sygdommen og beslutninger? Er der et særligt tidspunkt I har haft mest brug for at tale med en sygeplejerske omkring sygdom/beslutninger? Har der været nogle særlige udfordringer ift at tale om sygdommen/beslutninger i hjemmet/med sygeplejerskerne? Hvordan har du/du som pårørende, deltaget i forløbet? Hvordan har du/du som pårørende, deltaget i beslutninger?

	Supplerende: Kan du give et eksempel på en konkret beslutning der er blevet taget? Behandling/ift fremtiden? Har I taget andre beslutninger? Hvilken form for støtte har I modtaget I forbindelse med den beslutning?
Hjælpespørgsmål	Opfølgende spørgsmål: - Nikke - ”Hm” - Gentagelse af betydningsfulde ord - Lægge mærke til usædvanlige ord Sonderende spørgsmål: - Forfølger svaret ved at spørge: - Kan du sige noget mere? - Kan du beskrive? - Kan du give flere eksempler? Specificerende spørgsmål: - Hvad gjorde du så? - Hvad følte du/tænkte du? - Hvordan reagerede du? Strukturerede spørgsmål: - Nu vil jeg introducere et andet emne…. (Anvendes når et emne er udtømt, bruges til høflig at afbryde) Tavshed: - Tavshed anvendes så informanten får mulighed for at reflektere over svar og derved selv kan bryde tavsheden og komme med uddybende beskrivelser Fortolkende spørgsmål: - Er det rigtigt forstået at…? - Du mener altså….?

Appendix 9 - Interview guide focus group interviews – study 3

Dato: 14.05.20, kl. 14.45-16.00
Sted: OUH
Forplejning: Kaffe/the og chokolade
Moderator: Tine
Medmoderator: Karin

Baggrund:
Interviewguiden er udarbejdet mhp. på at få indsigt i sygeplejerskers erfaringer, oplevelser og udfordringer i at tale med patienter og familier om beslutninger ved livets afslutning.

Beslutninger ved livets afslutning er i denne sammenhæng defineret som, beslutninger relateret til behandling, men også tanker om den sidste tid samt at afklare egne ønsker før det bliver aktuelt at træffe beslutninger.

Forskningsspørgsmål:
Hvordan taler sygeplejersker med patient og familier om beslutninger ved livets afslutning?

Hvilke oplevelser og udfordringer har sygeplejersker ved at tale med patient og familier om beslutninger ved livets afslutning?

Først:

- ***Deltagerinformation – samtykkeerklæring*** (Information og underskrift)
  Tag jer en kop kaffe, lidt sødt og find jer tilpas.

Interviewmodel:
Introduktion: 14.45-14.50 (5 min)
Velkommen.
Vi er glade for at se jer alle og glæder os til at tilbringe de næste 5 kvarter sammen med jer.
Det vil primært være mig, der styrer interviewet og Karin sidder med som observatør.
Karin kan stille spørgsmål, hvis der er noget hun bliver nysgerrig på og/eller ønsker uddybet. Emnet i dag udspringer sig fra mit ph.d. projekt og det studie, som I har været en del af i afdelingen.
Formålet med at samle jer i dag er at få indsigt i jeres erfaringer, oplevelser og udfordringer i at tale med patienter og familier om beslutninger ved livets afslutning.

Interviewet kommer til at tage ca. 5 kvarter og bliver optaget på diktafon. Dette for at huske, hvad I fortæller. I er - og vil fremadrettet forblive anonyme. Alt hvad der bliver talt om i dag, vil blive behandlet *fortroligt*. I kan til enhver tid trække jeres samtykke tilbage.
Interviewet bliver transskriberet for at kunne huske, hvad I har sagt. I vil også blive tilbudt at læse interviewet igennem efter det er transskriberet.

Et *fokusgruppeinterview adskiller sig fra et "normalt" interview*, da det vil være jer der taler mest og diskuterer sammen. Hvis diskussionen kommer i en anden retning end dagens emne, vil jeg forsøge at hjælpe jer tilbage på sporet.
Der er ikke noget rigtig eller forkert svar og alle jeres oplevelser og erfaringer er vigtige at få frem og bringe i spil. Vi ønsker at få nuancer frem og I behøver ikke at være enige.

Disposition:

- Del 1: **Brainstorm** om beslutninger ved livets afslutning fra jeres perspektiv
- Del 2 & 3: Tager udgangspunkt i **jeres erfaringer, oplevelser** og **udfordringer** ved at I skriver på post its og **diskuterer** det skrevne med hinanden.
- Del 4. I **diskuterer temaer** fra observationer/interviewede patienter og familier/sygeplejersker
- Vi slutter af med lidt praktisk information hvor I skal notere lidt **baggrundsviden** om jer selv.

Spørgsmål inden vi starter?
Så går vi i gang:

Der udleveres post its og kuglepenne.

1) Brainstorm: 14.50-14.55 (5 min)
Hvad forstår I ved beslutninger ved livets afslutning?
Hvem har ansvaret for at der tales om beslutninger ved livets afslutning?
Gruppen får **3 min** til at tænke og skrive stikord ned
Vi får deres stikord

2) Erfaringer med at tale med patient og familier om beslutninger ved livets afslutning: 14.55-15.15 (20 min)
Hvad er jeres erfaringer med at tale med patienter og familier om beslutninger ved livets afslutning?
Hvordan inddrager I familien?

Gruppen får **3 min** til at tænke og skrive stikord ned

Diskuter gerne med hinanden
Kommenter på hinanden udtalelser
Perspektiver
Nuancer

Vi tager en runde - Hvem vil starte?

3) Hvad fremmer samtaler og hvilke udfordringer har I som sygeplejersker ved at tale med patient og familie om beslutninger ved livets afslutning: 15.15-15.35 (20 min)

For at komme i gang vil jeg bede jer om, at skrive **tre ting der fremmer** samtaler og **tre ting som udfordrer jer** når I taler med patient og familie om beslutninger ved livets afslutning.

Gruppen får **5 min** til at skrive ned

Diskuter gerne med hinanden

Kommenter på hinanden udtalelser
Perspektiver
Nuancer

Vi tager en runde - Hvem vil starte?

4) Diskussion af temaer: udtalelser fra patient, pårørende, sygeplejerske 15.35-16.00 (25 min)

Fra observationer og interviews fra patient, pårørende og sygeplejersker har jeg udledt fire overordnede temaer som skal danne baggrund for næste diskussion. Jeg vil læse et tema op af gangen og herefter skal I diskutere jeres umiddelbare tanker ift. temaet.

Diskuter gerne med hinanden
Kommenter på temaer/hinandens udtalelser
Perspektiver
Nuancer

TEMA 1: Tidspunkt for samtalerne

Der er ikke nogle systematisk tilgang til - og et bestemt tidspunkt for hvornår I sygeplejersker har samtaler om beslutninger ved livets afslutning. Nogle af patienterne har tidligt i deres sygdomsforløb haft brug for at afklare hvad der skal ske i fremtiden, andre har endnu ikke talt om det.

Eksempel: Udtalelse fra datter *"Jeg synes det kunne være rart at få talt om den kommende tid, jeg ved ikke om det er noget jeg har behov for nu, fordi jeg synes måske ikke vi er så langt at vi skal tage det nu hvad der skal ske den sidste tid, men det er okay vi gør det hvis hun (moderen) har brug for det, men på et eller andet tidspunkt synes jeg det er væsentligt at vi får talt om det, - og også inden hun bliver for dårlig til at tage beslutninger selv, det er rart at vi ligesom ved hvad hun gerne vil"*

Eksempel: Udtalelse fra sygeplejerske: *…., vi gør det ikke på nogen systematisk måde, men jeg oplever også at patienterne ikke er klar til at tale om det"*

Hvad gør I jer af tanker omkring rette tidspunktet for samtalerne? Hvordan vurderer I om patienten er klar til det? Hvad kunne en systematisk måde være?

TEMA 2: Indhold i samtalerne

Flere sygeplejersker fortæller at I/de har samtaler om beslutninger ved livets afslutning i ambulatoriet. Gennem observationer/interviews viser det sig at de beslutninger der bliver talt om i ambulatoriet ofte er behandlingsrelaterede, hvor der fx tales fordele/ulemper ved valg af kemoterapi, og ikke tanker/ønsker for den kommende/sidste tid.

Hvad tænker I om det? Hvad taler I med patienter og familier om? Hvordan forbereder I jer til samtalerne? Hvordan følger I op på samtalerne? Hvis I kunne ønske jer noget, hvad kan gøres for at forberede/holde/følge op på samtalerne?

Eksempel: Sygeplejerske: *"Jeg synes faktisk vi er gode til at tænke sådanne samtaler ind hvor vi taler om fx ønsker for fremtiden…."*

Eksempel: Patient: *"Sygeplejerskerne ved rigtig meget om fx bivirkninger til behandlingen, det taler vi selvfølgelig meget om når"*

TEMA 3: Betydning af at møde den samme sygeplejerske

Patienter og pårørende fortæller at det er af stor betydning, at det er den samme sygeplejerske de møder når de skal modtage kemoterapi og når de skal til scanningssvar. Det gør dem trygge og de oplever at der gives en anden form for omsorg og spørges ind til dem på en helt anden måde når. Når det ikke er den samme sygeplejerske de møder går informationer tabt, fx informationer om hvordan en patients tilstand har udviklet sig siden sidste kemobehandling, og samtalerne med patient og familie bliver overfladiske og handler om fx vejret, børn og børnebørn.

Hvad tænker I om det?

Udtalelse fra sygeplejerske: *"Jeg kan sagtens tage en svær samtale med en patient som jeg ikke kender, men jeg kan ikke være sikker på at jeg kommer hele vejen rundt om patienten og familien når jeg ikke kender dem"* Sygeplejerske

TEMA 4: Rammerne omkring samtalen

Temaet handler om at rammerne omkring samtalerne. Der er mange patienter på stuerne, de ligger tæt, nogle patienter har mange pårørende med. Ofte er der uro på stuerne fordi sygeplejerskerne fx skal hente handsker, venflon mv som er på det andet side af gardinet hvor en anden patient måske er i gang med en samtale.

Hvad tænker I om det? Hvad har rammerne af betydning for at samtalerne bliver udført? Hvis I kunne ønske jer noget, hvad skulle gøres?

Eksempel: Sygeplejerskes tanker omkring en episode hvor hun blev afbrudt i en samtale pga larm og uro: *"Skide irriterende…Nogle gange hjælper det med et lille gardin, men man kan jo stadig høre dem på den anden side. Nogle gange har patienterne brug for omsorg, og det er ikke let at tale og spørge ind til dem når der er fyldt i lokalet og et støjniveau som der var i dag"*

Slutteligt:

- Vores formål denne eftermiddag var at diskutere hvilke oplevelser og udfordringer I har som sygeplejersker når I skal tale med patient og familie om beslutninger ved livets afslutning– Synes I, at vi er kommet rundt om dette eller er der afslutningsvis noget I vil tilføje?

Tak for jeres tid og villighed til at deltage.

Appendix 10 - Participant information, for patients and family caregivers – study 3

Deltagerinformation

Jeg vil bede dig om at deltage i projektet *"Samtaler om beslutninger ved livets afslutning"*

Formål

Formålet med denne undersøgelse er at bidrage med vide om:

- Hvordan I som patient og familie oplever, at modtage kemoterapi og hvilken betydning det har for jeres hverdag
- Hvordan I som patient og familie oplever beslutningsprocessen ift. forskellige beslutninger i behandlingsforløbet
- Hvilken støtte I som patient og familie oplever at få – og hvilken støtte efterspørger I, som vi endnu ikke imødekommer.

Fremgangsmåde

Jeg vil følge dig og din familie ved enkelte fremmøder ved kemoterapibehandlingen og i ambulatoriet når I skal modtage scanningssvar. Ved at følge dig gennem forløbet og samtidig tale jer som familie, vil jeg få en større forståelse for jeres oplevelser med at modtage kemoterapi og jeres beslutninger knyttet til behandlingen og forløbet. Jeg vil også invitere dig og din familie til at deltage i et interview om jeres oplevelser i forbindelse med jeres behandling her på Onkologisk Afdeling. Samtalen kan finde sted her på afdelingen eller hjemme hos jer og denne vil indgå som en del af et forskningsprojekt sammen med andre. Samtalen vil vare omkring 1 times tid og vil blive optaget på bånd.

Anonymitet

Deltagelse er anonymt, og du vil være beskyttet af min tavshedspligt og vil til enhver tid kunne trække dig fra projektet uden begrundelse. Resultaterne vil blive udgivet i videnskabelige tidsskrifter. Hverken dit navn eller andre informationer, der kan identificere dig, vil være tilgængelige for samarbejdspartnere eller blive udgivet i publikationer eller rapporter. Projektet er anmeldt til Datatilsynet, journalnr: 18/60988. og Videnskabsetisk komité, journalnr: S-20172000-90.

Med venlig hilsen

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Informeret samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt.

Erklæring fra forsøgspersonen:

Jeg giver hermed samtykke til at deltage i forskningsprojektet, og tilladelse til at de projektansvarlige får adgang til min patientjournal med henblik på oplysninger om undersøgelser, kræftdiagnose og min kræftbehandling. Alle oplysninger vil blive behandlet fortroligt, og vil blive anonymiseret og opbevaret på Odense Universitetshospital under samme sikkerhedsforhold, som gælder min patientjournal

Jeg har fået skriftlig og mundtlig information og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage.

Jeg ved, at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage uden at miste mine nuværende eller fremtidige rettigheder til behandling.

Jeg giver samtykke til, at deltage i forskningsprojektet, og har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Navn: ____

Dato: ____________ Underskrift: ______________________________________

Erklæring fra den, der afgiver information:

Jeg erklærer, at forsøgspersonen har modtaget mundtlig og skriftlig information om projektet.

Efter min overbevisning er der givet tilstrækkelig information til, at der kan træffes beslutning om deltagelse i projektet.

Navnet på den, der har afgivet information: ___________________________

Dato: ____________ Underskrift: ______________________________________

Projektidentifikation: (Datatilsynet journalnr: 18/60988. Videnskabsetisk komité journalnr: S-20172000-90)

Appendix 11 - Participant information, for nurses – study 3

Deltagerinformation

Jeg vil bede dig om at deltage i projektet *"Samtaler om beslutninger ved livets afslutning"*

Formål

Formålet med denne undersøgelse er at bidrage med viden om:

- Hvordan understøtter I som sygeplejersker patient og familie når der skal træffes beslutninger i behandlingsforløbet
- Hvilke oplevelser og udfordringer har I som sygeplejersker når I skal understøtte patient og familie i at træffe beslutninger behandlingsforløbet

Fremgangsmåde

Jeg vil følge dig sammen en patient og familie ved enten kemoterapibehandlinger eller lægesamtale. Ved at følge jer og tale med jer, vil vi få en større viden om hvordan I som sygeplejersker støtter patient og familie i behandlingsforløbet og i de beslutninger der skal tages undervejs. I den forbindelse vil jeg også invitere dig til at deltage i et fokusgruppe interview, sammen med andre sygeplejersker fra afdelingen.

Anonymitet

Deltagelse er anonymt, og du vil være beskyttet af min tavshedspligt og vil til enhver tid kunne trække dig fra projektet uden begrundelse. Resultaterne vil blive udgivet i videnskabelige tidsskrifter. Hverken dit navn eller andre informationer, der kan identificere dig, vil være tilgængelige for samarbejdspartnere eller blive udgivet i publikationer eller rapporter. Projektet er anmeldt til Datatilsynet, journalnr: 18/60988. og Videnskabsetisk komité, journal nr: S-20172000-90.

Med venlig hilsen

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Informeret samtykke til deltagelse i et sundhedsvidenskabeligt forskningsprojekt.

Forskningsprojektets titel:

Samtaler om beslutninger ved livets afslutning

Erklæring fra forsøgspersonen:

Jeg har fået skriftlig og mundtlig information og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage.

Jeg ved, at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage.

Jeg giver samtykke til, at deltage i forskningsprojektet, og har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Navn: ____

Dato: ____________ Underskrift: ____________________________________

Erklæring fra den, der afgiver information:

Jeg erklærer, at _____ har modtaget mundtlig og skriftlig information om projektet.

Efter min overbevisning er der givet tilstrækkelig information til, at der kan træffes beslutning om deltagelse i projektet.

Navnet på den, der har afgivet information: __________________________

Dato: ____________ Underskrift: ____________________________________

Projektidentifikation: (Datatilsynet journalnr: 18/60988. Videnskabsetisk komité journalnr: S-20172000-90)

Papers

Paper 1:
Ikander T, Jeppesen SS, Hansen O, Raunkiær M, Dieperink KB.
Treatment expectations and quality of life during palliative chemotherapy among patients and family caregivers affected by thoracic cancer: A longitudinal prospective study.
BMC Palliative Care. 2021 Feb 26; 20(1):37.

Paper 2:
Ikander T, Hansen O, Raunkiær M, Dieperink KB.
Nurses' involvement in end-of-life discussions with incurable cancer patients and their family caregivers: An integrative review.
Palliative & Supportive Care. 2021 May 6:1-12. Doi: 10.1017/S1478951521000596. Epub ahead of print. PMID: 33952373.

Paper 3:
Ikander T, Dieperink KB, Hansen, O, Raunkiær M.
Patient, family caregiver, and nurse involvement in end-of-life discussions during palliative chemotherapy: a phenomenological hermeneutic study
Accepted for publication in Journal of Family Nursing 27.06.21.