



Differences in palliative care needs between cancer patients and non-cancer patients at the start of specialized palliative care: A nationwide register-based study

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Abstract

Background: Patients with non-cancer disease are less likely to receive specialized palliative care than cancer patients. To be able to provide the best specialized palliative care, it is important to understand palliative care needs of non-cancer patients and whether the type and level of needs differ from those of cancer patients. Large studies including both cancer and non-cancer patients, using validated needs-assessment-tools, are needed to understand differences in palliative care needs at admittance to specialized palliative care.

Aims: To compare palliative care needs at the start of palliative care for cancer and non-cancer disease.

Design: Six-year nationwide register-based study.

Setting/participants: This study included patients from all Danish specialized palliative care services (hospice care, hospital-based palliative care, home-based palliative care, or consultation) who completed a need-assessment-questionnaire. Ordinal logistic regression was performed to study the association between diagnosis and needs.

Results: Cancer patients had a higher probability of receiving specialized palliative care. Of the 44,315 palliative care admissions included in this study, 93.3% were on cancer patients. Independent of diagnosis patients experienced on average six needs and high levels of fatigue and impaired physical functioning. Non-cancer patients had significantly higher odds of insomnia, fatigue and impaired emotional functioning, physical functioning, and quality of life whereas cancer patients had higher odds of pain (except for patients with neurological disease).

Conclusions: The higher levels of several symptoms/problems among non-cancer patients compared to cancer patients suggests that referral to specialized palliative care should be improved for non-cancer patients perhaps by improving identification of palliative needs.

Keywords

Palliative care, symptom assessment, quality of life, cardiovascular diseases, neurological diseases, lung diseases, kidney diseases, cancer

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What is already known about the topic?

- Access to palliative care is limited, and cancer patients have much higher access than patients with life threatening non-cancer disease. The capacity of palliative care is expected to be even more challenged in the future due to the aging population.
- Studies of cancer and non-cancer patients have found high levels of palliative care needs (symptoms/problems) at the start of palliative care.
- European studies comparing palliative care needs of cancer and non-cancer patients using the same patient self-report tool across diagnostic groups at referral or start of palliative care are scarce

What this paper adds?

- The symptom burden was found to be high: across all diagnostic groups at least 9 out of 10 patients experienced fatigue and low physical functioning at the start of palliative care. On average, cancer and non-cancer patients experienced six needs (four symptoms/problems at a severe level).
- Non-cancer patients had a higher risk of experiencing insomnia, fatigue, impaired emotional functioning, impaired physical functioning, and low quality of life, compared to cancer patients.
- Cancer patients had a higher risk of pain compared to non-cancer patients, except for neurological patients who had the highest risk of pain.

Implications for practice, theory, or policy

- The study suggests that access to palliative care should be improved for non-cancer patients who have as many (or more) palliative care needs as cancer patients.
- Future studies should assess palliative care needs repeatedly over time to increase the knowledge about which patients with cancer and other diagnoses should be referred to palliative care at which stage in their trajectories.

Introduction

The capacity of specialized palliative care is limited in many countries and this problem is expected to increase in the future due to the aging population. Patients with cancer are more likely to get access to palliative care services than patients with other advanced chronic diseases^{1–5} and to obtain access earlier,⁶ but reports from the US and Denmark indicate the proportion of non-cancer patients admitted to palliative have increased in the last decade.^{2,7} Based on the proportion dying from chronic diseases, it is estimated that around 75% in high income countries would benefit from palliative care before they die because they are expected to experience palliative care needs as their disease progress.^{8,9}

Different screening tools have been developed to help clinicians identify patient in need of palliative care, for example, SPICT, NECPAL, and the Gold Standard Framework.^{10,11} When applying one of the tools the proportion identified with a need for palliative care have varied widely (4.5% to 87.0%).¹⁰ The variations may be due to the use in different settings (primary care, hospital department, general practice), different diagnostic groups and different screening tools. Nationwide data from different countries have shown that only 17% of those who die in Sweden and 19% of those who die in Denmark receive specialized palliative care before they die^{2,12} whereas 46% receive specialized palliative care in the last year of life in Australia.⁴

According to the World Health Organization palliative care should depend not on diagnosis but on the patients' palliative care needs.⁵ This is supported by previous studies finding high prevalence of several problems (e.g. pain, dyspnea, and fatigue) for patients admitted to palliative with cancer as well as with non-cancer diseases.^{13–17}

As more non-cancer patients are being admitted to specialized palliative care it is important to understand their palliative care needs and how they differ from the needs of cancer patients to be able to plan and provide the best palliative care for all patients. If the level of palliative care needs is different for cancer and non-cancer patients at admittance to specialized palliative care it may reflect that doctors treating patients with life threatening non-cancer diseases and cancer, respectively, are not equally aware of the patients' palliative care needs and perhaps have different referring practice to specialized palliative care. To be able to understand whether the level of palliative care needs differs across diagnostic groups at admittance to palliative care, studies are, however, needed where palliative care needs among cancer and non-cancer patients are identified and compared using the same measurement tool and preferably including patients from several palliative care services. We only identified one study that included both cancer and non-cancer patients where a validated tool was used for assessment of palliative care needs, that is, a study from the US where 879 cancer and non-cancer patients reported their quality of life and level of

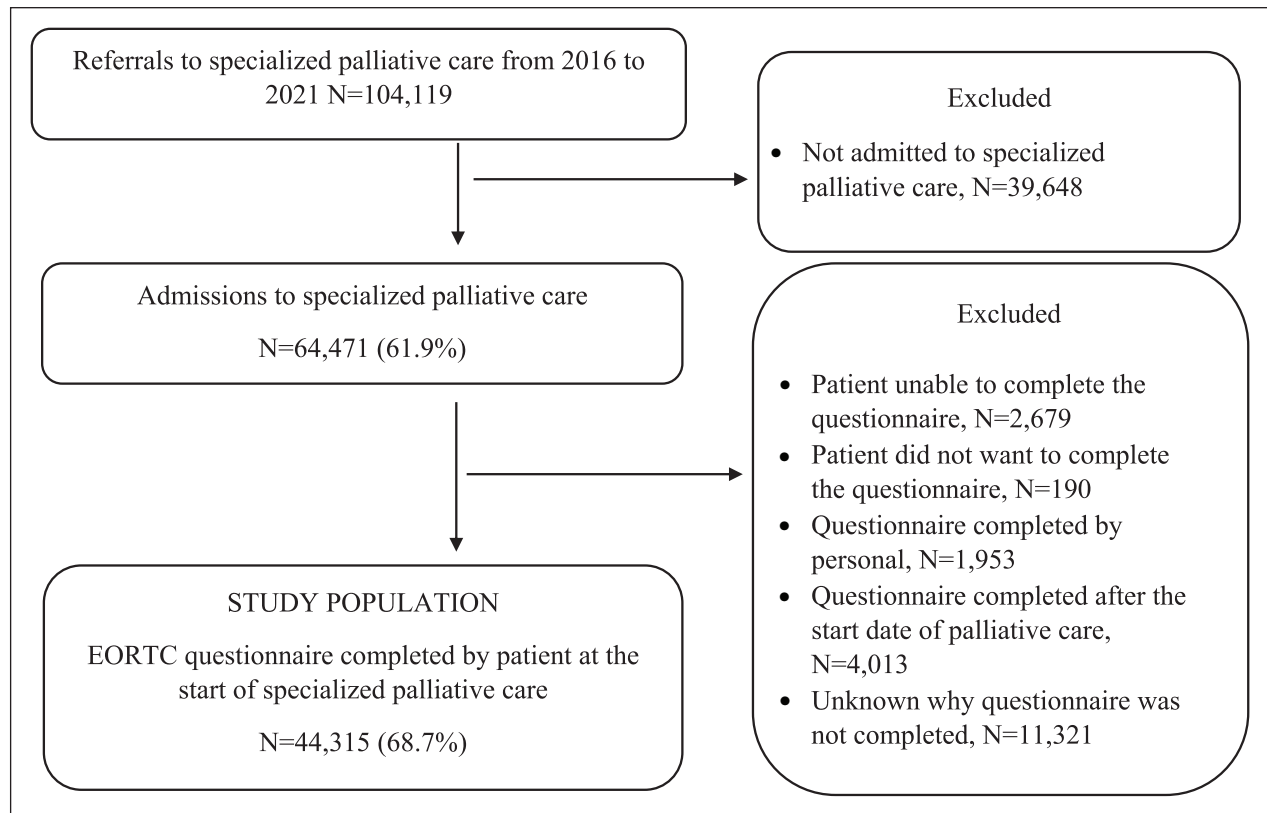


Figure 1. Flowchart of patients included in the study.

pain, dyspnea, depression, and fatigue at the first palliative care consultation.¹⁶

The aims of this study were to investigate the average levels, prevalence and numbers of palliative care needs (i.e. symptoms and problems) among cancer and non-cancer patients at the start of specialized palliative care in Denmark. It was also an aim to study the association between diagnostic group (cancer vs the other diagnostic groups) and the probability of experiencing different palliative care needs controlled for the effect of sex, age, social factors, type of palliative care service and survival time.

Methods

Study design

The study is a register-based study using data from the Danish Palliative Care Database. Data from all 42 specialized palliative care services in Denmark were included.

Setting

In Denmark, specialized palliative care is provided in hospices and palliative care teams in hospitals and in 2022, there were 42 specialized palliative care services in Denmark.² Of the 42 services: 15 (35.7%) were hospital based palliative care teams delivering palliative care in

their own hospital department, providing specialized consultations in other hospital departments and providing home-based palliative care; 8 teams (19.0%) also had beds for inpatients; 15 hospices only had inpatient beds (35.7%); and the remaining 4 hospices (9.5%) had inpatient beds and provided home-based palliative care. To get access to specialized palliative care, a referral by a physician is required. In the period 2016–2021, there were 104.119 referrals to specialized palliative care in Denmark (see Figure 1) and 19.3% were from the general practitioner, 68.7% from a non-palliative hospital department, 11.3% from another specialized palliative care service and 0.3% from others.

Data collection

The study included nationwide data from the Danish Palliative Care Database.¹⁸ In Denmark, it is mandatory for all specialized palliative care services to report information on patients referred to them to the database and therefore, all patients referred to specialized palliative care are included in the database. In each specialized palliative care service, a health care professional completes a questionnaire on paper for patients referred to their palliative care service with sociodemographic and clinical information. This information is registered online by a staff from the palliative care service in the Danish Palliative

Care Database together with answers from patient completed need assessment questionnaires (i.e. EORTC QLQ-C15-PAL-questionnaires).

Because the main purpose of the Danish Palliative Care Database is quality improvement/development it is not necessary to ask for patients' consent to register their information in the database. When data from the database are used for research the board of the database and the Danish Data Protection Agency needs to approve it.

Need assessment

Palliative need assessment data registered in the database are from the EORTC QLQ-C15-PAL questionnaire completed by patients either 1–3 days prior to the start date of specialized palliative care if the patient have been asked by either the specialized palliative care service at referral or by the referring general practitioner or referring hospital department to do so, but in most cases the patient is asked to complete a questionnaire at the start date of specialized palliative care. Patients are only asked to complete the questionnaire if the healthcare professionals believe the patient is capable of completing it and therefore, patients with impaired cognition are not asked. Most patients completes on paper but some use their computer, tablet or smartphone.

The EORTC QLQ-C15-PAL is a shortened version of the EORTC QLQ-C30 adapted to patients in palliative care.¹⁹ EORTC QLQ-C15-PAL has been validated in several studies^{19–27} and its psychometric quality was evaluated as one of the best among 39 self-report instruments assessing health related QOL of advanced cancer patients for use in palliative care.²⁸ The EORTC QLQ-C15-PAL questionnaire assess the severity of nine symptoms/problems by two multi-item function scales (physical and emotional functioning), two multi-item symptom scales (fatigue and pain) and five single-item symptom scales (dyspnea, insomnia, appetite loss, constipation and nausea) together with a single item on overall quality of life. Patients answer how much they have experienced each symptom and problem on a 4-point-scale from “not at all” to “very much.” A 7-point scale is used to assess overall quality of life, where 1 corresponds to “very poor” and 7 to “excellent” quality of life. All questions refer to the past week except for physical functioning where no time frame is specified.¹⁹

Population

In this study the inclusion criteria were:

- Start of specialized palliative care in the period from 2016 to 2021
- 18+ years of age
- Answered the EORTC QLQ-C15-PAL within the time limit, that is, from three days before the start of specialized palliative care to the day of start.

Variables

Outcomes

- Pain
- Dyspnea
- Insomnia
- Appetite loss
- Constipation
- Nausea
- Fatigue
- Emotional function
- Physical function
- Overall quality of life
- Number of symptoms/problems (range 0–9)
- Number of severe symptoms/problems (range 0–9)

Explanatory variable:

- Diagnosis (cancer vs non-cancer diagnostic groups). The other diagnostic groups were “cardiovascular disease,” “lung disease,” “neurological disease,” “kidney disease,” and “other non-cancer disease.”

Covariates (possible confounders):

- Sex
- Age
- Type of palliative service (hospice, palliative care team)
- Living situation (living alone in private residence, living together with others in private residence or living in elderly/nursing home). Elderly and nursing homes in Denmark are for old people with possible disabilities. Nursing staff are employed at the nursing homes, whereas people living in elderly homes need to be able to take care of them self, most of the day. The nursing and retirement homes are administered by the state or private organizations.
- Having children (i.e. <18 and ≥18 years of age)
- Days until death from the start of specialized palliative care

Statistics

The EORTC QLQ-C15-PAL scales were converted into 0–100 scales according to the scoring manual.^{19,29} Higher function scale scores represent better physical or emotional functioning, or quality of life whereas higher symptom scale scores represent worse symptoms.

Each of ten symptom/problem/quality of life-scales was dichotomized into two new variables. One variable were computed for experiencing a symptom/problem (symptom scores ≥33, functional scores ≤67) or not (symptom score <33, function score >67) and one for experiencing a severe symptom/problem (symptom scores ≥ 66, functional scores ≤34) or not (symptom

scores <66, functional scores >34). Having a symptom/problem corresponded to reporting the symptom/problem at least “a little” and having a severe symptom/problem corresponded to reporting it at least “quite a bit.”

For each patient the number of symptoms/problems and severe symptoms/problems was calculated with a possible range of 0–9, excluding overall quality of life because it was not considered as a specific symptom or problem. For each symptom/problem the problem prevalence and severe problem prevalence, respectively, were calculated as the proportion of patients experiencing the problem and severe problem, respectively.

Symptom/problem mean scores, mean number of symptoms and prevalence of each symptom/problem were computed according to diagnostic group.

Ordinal logistic regression analyses were performed to study the associations between diagnosis and each outcome while controlling for the effect of sex, age, type of palliative service (hospice, palliative care team), living situation (i.e. type of residence and cohabitation), having children and days until death from the start of specialized palliative care. Patient was included as a random effect in the model to account for the fact that some patients were admitted to more than one palliative care service and thus completed EORTC QLQ-C15-PAL at the start of each admittance. Of the 44,315 admittances to specialized palliative care included in this study, 36,564 (82.5%) were from the first palliative care service the patient were admitted to and the remaining 7751 (17.5%) were from later admittances to other palliative care services.

The proportion of patients with cancer and non-cancer, respectively, who were referred and admitted to specialized palliative care (the nominator) of those who died during the six-year study period from 2016 to 2021 (the denominator). The denominator, that is, number of deaths from different causes from 2016 to 2021, was obtained from the Danish Causes of Death Registry.³⁰ The proportion of referred and admitted, respectively, of the deaths in the period 2016–2021, were computed according to death from; cancer, cardiovascular disease, neurological disease, respiratory disease, kidney disease, and the remaining causes of deaths (excluding pregnancy and birth complications, perinatal diseases, congenital malformations and chromosomal anomalies, accidents, suicide and homicide).³⁰

The analyses were performed using SAS Enterprise Guide 7.1.

Results

Referral and admittance to specialized palliative care

During the study period from 2016 to 2021, 68,854 patients were referred to specialized palliative and 52,345 received specialized palliative care. According to the

Danish Causes of Death Registry, during the same period from 2016 to 2021, there were 95,274 cancer deaths in Denmark and 203,537 non-cancer death (excluding pregnancy and birth complications, perinatal diseases, congenital malformations and chromosomal anomalies, accidents, suicide and homicide).³⁰ The proportion of cancer patients who were referred and admitted, respectively, to specialized palliative care before death were 65% (61,714/95,274) and 50% (48,087/95,274) which was much higher than for non-cancer patients with only 4% referred (7140/203,537) and 2% admitted (4258/203,537) (Supplemental Table 1). The proportion referred and admitted for the specific non-cancer diagnostic groups can be seen in Supplemental Table 1.

Characteristics of the study population

This study only included patients referred and admitted to specialized palliative care with a completed need-assessment-questionnaire. In the period from the beginning of 2016 to the end of 2021, 68,854 patients had in total 104,119 referrals to specialized palliative care (66.2% one referral, 24.0% two referrals, 9.8% three or more) (Figure 1). Of the 104,119 referrals, 64,471 ended with an admission (61.9%). The 64,471 admissions were on 52,345 patients (81.1% one admission, 18.0% two admissions, 0.8% three or more admissions). In 44,315 of the 64,471 admissions (68.7%) the patient completed a EORTC QLQ-C15-PAL questionnaire at the start of palliative care and were included in the study (Figure 1). The proportion of admitted patients who answered the questionnaire differed according to diagnosis (lung disease 73.0%, cancer 69.3%, kidney disease 65.1%, cardiovascular disease 60.0%, neurological disease 49%, other non-cancer diseases 52.6%).

The study included 44,315 admissions to specialized palliative care where a EORTC QLQ-C15-PAL questionnaire had been completed at the start of specialized palliative care, mainly by cancer patients, that is, 41,345 (93%) but 2970 (7%) by patients with non-malignant diagnoses (lung disease: 3%, cardiovascular disease: 1%, neurological disease: 1%, kidney disease: 1% and other non-malignant disease: 1%) (Table 1). Most cancer patients received specialized palliative care in the hospital or at home (66.4%) that is, by a palliative care team, whereas the patients with non-cancer disease most often received specialized palliative care in a hospice (Table 1). Survival time from the start of specialized palliative care differed between diagnostic groups. Patients with neurological disease and lung disease survived the longest, that is, median survival of 108 and 105 days, respectively, whereas patients with kidney disease had the shortest median survival time of 33 days (Table 1). Mean age for most diagnostic groups was around 70 years, but patients with cardiovascular disease were older (76 years). Most patients lived in private homes, but it was more common

Table 1. Characteristics from specialized palliative care admissions in 2016–2021 where the patient completed EORTC QLQ-C15-PAL at the start of palliative care.

Patient characteristics	Diagnostic group											
	Cancer		Cardiovascular disease		Neurological disease		Lung disease		Kidney disease		Other non-cancer disease	
	N	%	N	%	N	%	N	%	N	%	N	%
Total	41,345	100	560	100	457	100	1306	100	235	100	412	100
Type of palliative service admitted to												
Hospice	13,907	33.6	330	58.9	325	71.1	848	64.9	165	70.2	269	65.3
Palliative care team	27,438	66.4	230	41.1	132	28.9	458	35.1	70	29.8	143	34.7
Survival time (number of days from admittance to death)	40,278		521		419		1176		186		333	
Range (days)		0–2501		0–1678		0–1783		0–1999		0–1762		0–1598
Mean (days)		103.7		153.0		234.0		250.6		157.5		155.8
Median (days)		40		34		108		105		33		46
Sex												
Female, N (%)	21,103	51.0	221	39.5	204	44.6	656	50.2	106	45.1	200	48.5
Male, N (%)	20,242	48.9	339	60.5	253	55.4	650	49.8	129	54.9	212	51.5
Age groups												
18–49 years	2430	5.9	22	3.9	31	6.8	38	2.9	36	15.3	61	14.8
50–59 years	5283	12.8	32	5.7	63	13.8	96	7.4	21	8.9	64	15.5
60–69 years	10,945	26.5	72	12.9	120	26.3	337	25.8	49	20.9	83	20.2
70–79 years	14,704	35.6	177	31.6	197	43.1	571	43.7	65	27.7	119	28.9
80 years or older	7983	19.3	257	45.9	46	10.1	264	20.2	64	27.2	85	20.6
Range (years)		18–101		22–97		22–91		29–100		25–96		18–100
Mean (years)		69.4		76.3		68.0		71.5		68.2		66.3
Median (years)		71		79		70		73		71		69
Living situation												
Private residence, alone	40,085		544		448		1276		225		391	
Private residence, with others	14,434	36.0	216	39.7	100	22.3	530	41.5	110	48.9	156	39.9
Elderly home or nursing home	24,542	61.2	293	53.9	289	64.5	652	51.1	103	45.8	205	52.4
Children	1109	2.8	35	6.4	59	13.2	94	7.4	12	5.3	30	7.7
Yes, below 18 years	40,040		540		448		1,254		222		395	
Yes, 18 years or above	2454	6.1	13	2.4	23	5.1	38	3.0	14	6.3	37	9.4
No	32,507	81.2	467	86.5	369	82.4	1080	86.1	150	67.6	278	70.4
	5079	12.7	60	11.1	56	12.5	136	10.9	58	26.1	80	20.3

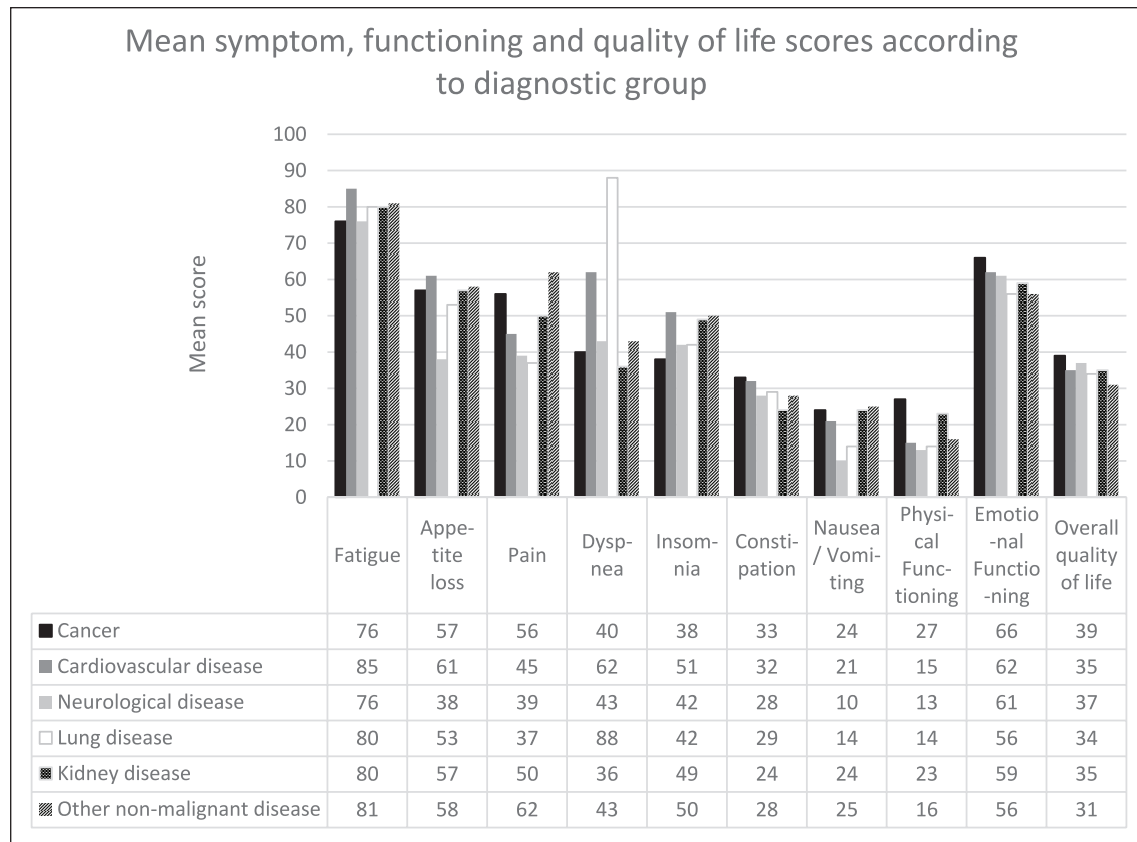


Figure 2. Mean symptom, functioning and overall quality of life scores according to diagnostic group. The worst symptom score is 100 whereas the worst functioning and quality of life score is 0.

for patients with neurological disease to live in elderly homes compared to patients with other diagnoses. Most patients had children (74–89%).

Mean symptom, problem, and quality of life scores

Across diagnostic groups, the highest mean symptom scores were found for fatigue (mean scores 76–85), appetite loss (means 38–61), pain (means 37–62) and dyspnea (means 36–88) (Figure 2). Low (poor) physical functioning (means 13–27) and overall quality of life (means 31–39) were seen across all diagnostic groups (Figure 2). The largest difference between diagnostic groups was seen for dyspnea where lung patients had a much higher mean score than other diagnostic groups (means score 88 vs 36).

Proportions of symptoms and problems

The proportions of patients reporting a symptom or a problem (minimum “a little”) were high for most symptoms and problems (Figure 3). For all diagnostic groups at least 90% experienced fatigue (95.3–97.9%), impaired

physical function (89.9–99.0%) and impaired quality of life (90.6–93.7%) (Figure 3). Appetite loss, pain, dyspnea and insomnia were experienced by more than half of the patients (Figure 3). Most patients experienced severe levels of fatigue (74.9–87.2%) and impaired physical functioning (73.4–93.1%) and more than half had severely impaired quality of life (54.2–65.1%). Around a third or more of patients experienced severe appetite loss (36.3–65.0%), pain (30.4–59.7%), dyspnea (32.2–92.5%), and insomnia (37.5–50.6%) (Figure 4).

The largest difference in the proportion of patients experiencing symptoms/problems and severe symptoms/problems between diagnostic groups, were seen for dyspnea, pain, and appetite loss.

Average number of symptoms and problems

Across diagnostic groups, the average number of symptoms/problems reported on the EORTC QLQ-C15-PAL was around six (cancer: 6.1, cardiovascular: 6.4, neurological: 5.7, lung: 6.3, kidney: 5.9, other non-cancer: 6.4) and the average number of severe symptoms/problems was around four (cancer: 3.8, cardiovascular: 4.6, neurological: 3.6, lung: 4.4, kidney: 4.0, other non-cancer: 4.3).

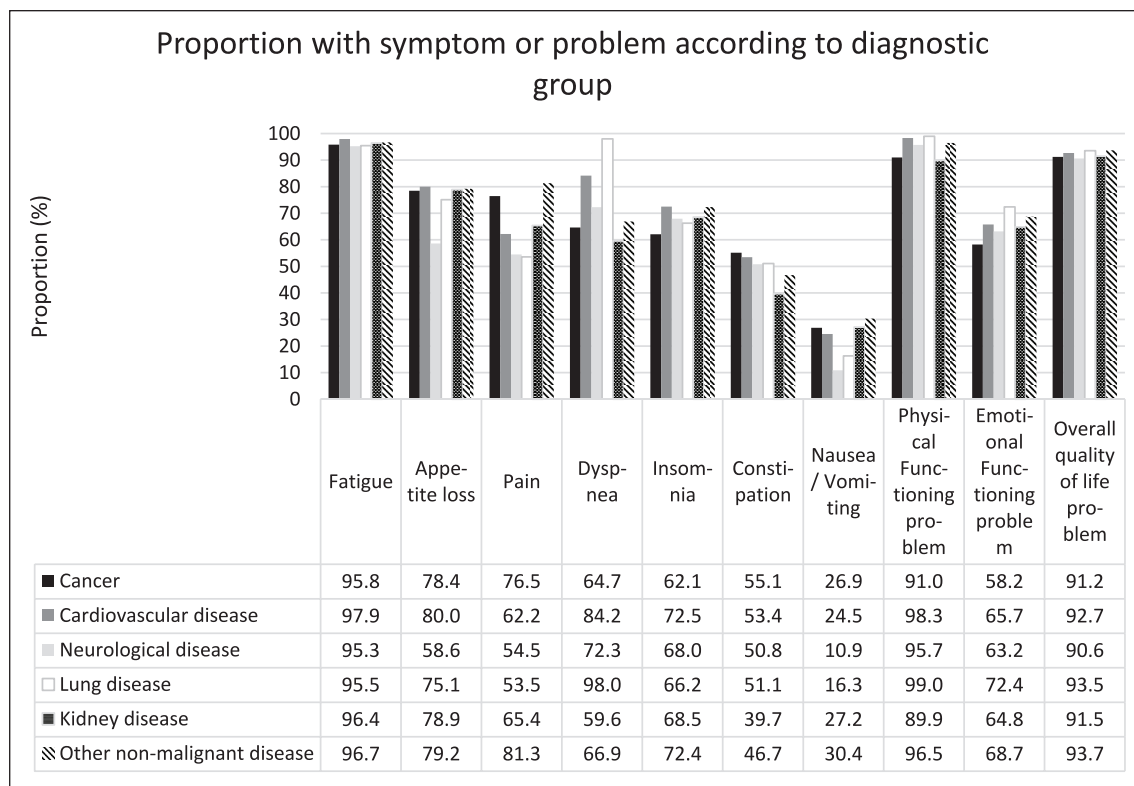


Figure 3. Proportions of patients experiencing symptoms and problems at least “a little” according to diagnostic group.

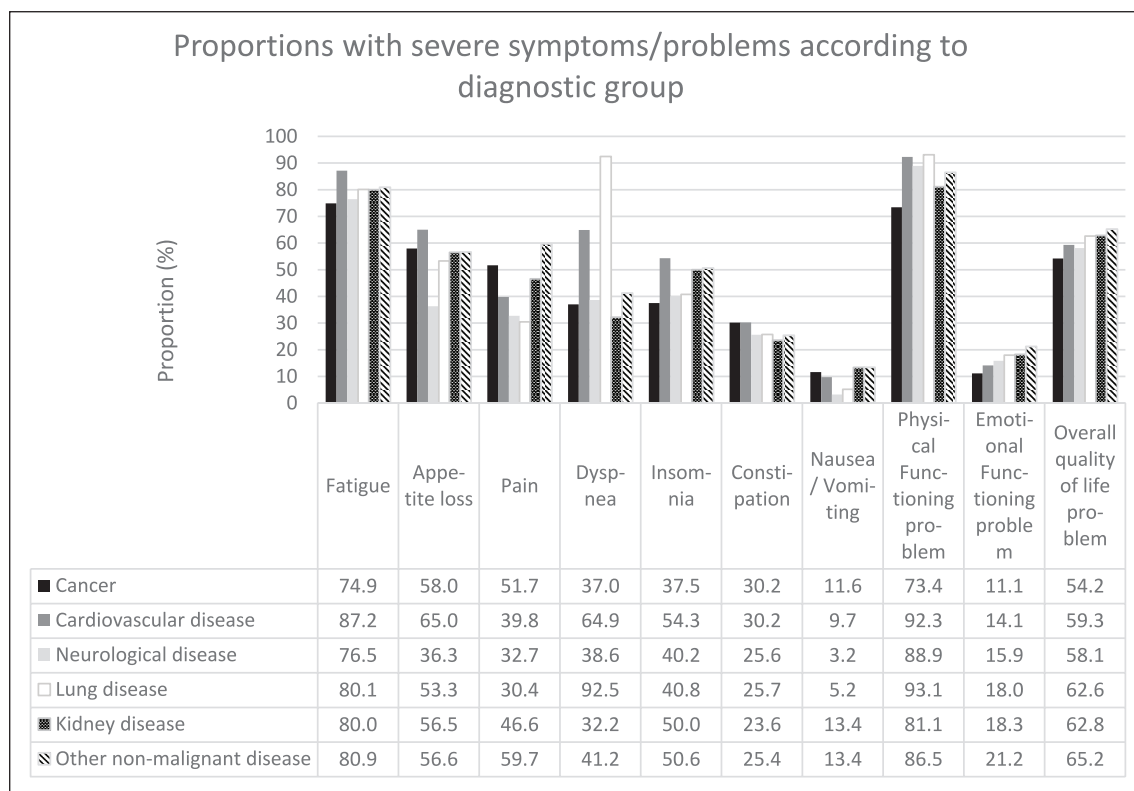


Figure 4. Proportions of patients experiencing severe levels of symptoms and problems according to diagnostic group.

Table 2. Odds ratios and 95% CI for higher levels of symptoms, lower functioning, lower QOL and higher number of symptoms/problems and severe symptoms/problems, respectively, for patients with non-malignant diagnoses compared to cancer patients from ordinal logistic regression.

Outcomes	Odds ratio and 95% CI for higher levels of symptoms, lower functioning, lower QOL and higher number of problems and severe problems, respectively, for patients with non-malignant diagnoses compared to cancer patients					
	Cancer* N = 41345	Cardio-vascular disease N = 560	Neurological disease N = 457	Lung disease N = 1306	Kidney disease N = 235	Other non-cancer disease N = 412
Pain	1.0 (ref.)	0.6 (0.5;0.7)	1.3 (1.1;1.6)	0.4 (0.4;0.5)	0.8 (0.6;1.1)	0.4 (0.3;0.5)
Dyspnea	1.0 (ref.)	3.2 (2.7;3.8)	1.6 (1.3;1.9)	17.6 (15.3;20.2)	1.0 (0.7;1.3)	1.4 (1.2;1.7)
Insomnia	1.0 (ref.)	2.2 (1.9;2.6)	1.7 (1.4;2.0)	1.3 (1.2;1.5)	1.6 (1.2;2.1)	1.3 (1.1;1.5)
Appetite loss	1.0 (ref.)	1.3 (1.1;1.5)	1.2 (0.9;1.4)	1.0 (0.9;1.1)	1.3 (1.0;1.7)	0.5 (0.4;0.6)
Constipation	1.0 (ref.)	1.0 (0.8;1.2)	0.8 (0.7;1.0)	1.0 (0.9;1.1)	0.6 (0.5;0.8)	0.9 (0.7;1.1)
Fatigue	1.0 (ref.)	2.1 (1.8;2.5)	1.7 (1.4;2.1)	1.8 (1.6;2.0)	1.8 (1.3;2.3)	1.4 (1.2;1.7)
Nausea/vomiting	1.0 (ref.)	0.9 (0.8;1.1)	1.0 (0.8;1.2)	0.6 (0.5;0.6)	1.2 (0.9;1.5)	0.4 (0.3;0.5)
Low emotional functioning	1.0 (ref.)	1.4 (1.2;1.7)	1.8 (1.4;2.2)	1.9 (1.7;2.2)	1.5 (1.1;1.9)	1.4 (1.1;1.6)
Low physical functioning	1.0 (ref.)	2.4 (2.0;2.8)	3.8 (3.1;4.6)	3.4 (3.1;3.8)	2.3 (1.8;3.0)	6.9 (5.7;8.4)
Low quality of life	1.0 (ref.)	1.4 (1.2;1.7)	2.0 (1.6;2.5)	1.7 (1.5;1.9)	1.6 (1.2;2.1)	1.5 (1.2;1.8)
Higher number of symptoms/problems	1.0 (ref.)	1.5 (1.3;1.8)	1.5 (1.2;1.8)	1.4 (1.3;1.6)	1.1 (0.8;1.4)	0.8 (0.7;1.0)
Higher number of severe symptoms/problems	1.0 (ref.)	2.1 (1.7;2.4)	1.7 (1.3;2.0)	2.0 (1.8;2.3)	1.6 (1.2;2.1)	1.0 (0.8;1.2)

Significant differences between cancer and each non-malignant diagnosis in bold.

Analyses were controlled for the effect of sex, age, type of palliative service, living situation, having children, and survival time from the start of palliative care.

Odds ratios >1 indicate more severe symptoms, lower (worse) functioning or lower quality of life, higher number of symptoms/problems or higher number of severe symptoms/problems among non-cancer patients compared to patients with cancer.

*Diagnostic group was significantly associated with all outcomes ($p < 0.05$).

Patients with cardiovascular, lung, and other non-cancer diseases, thus, had the highest mean numbers of symptoms/problems and severe symptoms/problems.

Regression analyses

In the ordinal logistic regression analyses, diagnostic group was significantly associated with all the outcomes ($p < 0.05$). Non-cancer patients had a markedly higher odds for experiencing a low physical functioning compared to cancer patients (OR between 2.3 and 6.9) but also higher odds for experiencing insomnia (OR between 1.3 and 2.2), fatigue (OR between 1.4 and 2.0), low emotional functioning (OR between 1.4 and 1.9) and low quality of life (OR between 1.4 and 2.0) (Table 2). Non-cancer patients had lower odds of experiencing pain compared to cancer patients (OR between 0.4 and 0.8), except for patients with neurological disease who had higher odds (OR = 1.3). Patients with cardiovascular, neurological and lung diseases, respectively, had the highest odds for experiencing a higher number of symptoms/problems and severe symptoms/problems (Table 2). The largest difference between diagnoses was for dyspnea where, especially, patients with lung disease had very high odds compared to cancer patients (OR 17.6, 95% CI: 15.3;20.2).

Discussion

Main findings

Patients with cancer and other diseases experience a high level of several symptoms and problems at the start of specialized palliative care. Regardless of diagnoses, patients reported on average around six symptoms/problems (rated as at least "a little") and around four severe symptoms/problems (rated as "quite a bit" or "very much"). Except for pain, the overall picture was that cancer patients experienced lower levels of symptoms/problems compared to non-cancer patients, although exceptions were seen. The difference between cancer patients and non-cancer patients was most clear for physical functioning, where non-cancer patients had higher odds of low physical function compared to cancer patients. Non-cancer patients also had higher odds of insomnia, fatigue, low emotional functioning, and low quality of life, whereas cancer patients had higher odds of pain compared to most non-cancer diagnostic groups.

What this study adds

This nationwide study documented complex palliative care needs (high levels of symptoms/problems and several symptoms/problems) among cancer and non-cancer

patients. Because the same tool (EORTC QLQ-C15-PAL) was used at the start of palliative care across diagnostic groups, this study was able to show similarities and differences in palliative care needs for cancer patients compared to non-cancer patients, that is, making a more valid comparison than what would be possible by comparing palliative care needs between studies that included only cancer patients or only non-cancer patients and perhaps used different symptom assessment tools. Survival time from the start of palliative care differed between diagnostic groups, but we controlled for survival time in the regression analyses when we compared palliative care needs between the diagnostic groups.

Previous studies assessing the prevalence of palliative care related problems in either cancer or non-cancer patients admitted to palliative care have also shown high prevalences of several problems among cancer and non-cancer diagnostic groups.^{13–17} A study from US, where palliative care needs were compared between 629 cancer and 250 non-cancer patients (heart failure, COPD, and advanced renal disease) using the Edmonton Symptom Assessment System, found moderate to severe levels of fatigue in more than half of patients and moderate to severe pain and dyspnea, respectively, by 22% to 50% of the patients across diagnoses.¹⁶

Although complex symptomatology was found across all diagnostic groups in our study, the overall picture was that non-cancer patients had higher odds of several symptoms, had a higher number of severe symptoms/problems and had poorer emotional and physical functioning, as well as lower quality of life. On the other hand, the risk of pain was higher among cancer patients compared to most groups of non-cancer patients, with the exception of patients with neurological disease who had the highest risk of pain. The study from US also found that non-cancer patients more often experienced severe dyspnea and had lower performance status compared to cancer patients but less often experienced severe pain.¹⁶ As opposed to our study, the US study found that the risk of severe fatigue was higher among cancer patients and found no significant differences in the risk of depression for cancer patients compared to non-cancer patients.¹⁶

The palliative care needs (symptoms and problems) found for cancer and non-cancer patients at admittance to specialized palliative care in this (and in previous research), underline that access to palliative care should not depend on diagnoses as stated by World Health Organization.⁵ Palliative care needs have also been compared for cancer and non-cancer patients with life threatening disease in the health care system outside specialized palliative care, that is, in two studies from the US, one from Canada and a small pilot study from UK.^{31–34} Some of these studies found differences in some (but not all) physical symptoms, but none of the studies found significant differences in non-physical problems.

The palliative care needs found across diagnostic groups together with the lower referral and admittance to specialized palliative care for non-cancer patients, strongly suggests that referral and access to specialized palliative care for non-cancer patients should be improved. Part of the solution to increase awareness of palliative care needs and referral to specialized palliative care for non-cancer patients is to use clinician administered tools to identify patients in need of palliative care (e.g. SPICt and NACPAL)¹⁰ and also to make patients with life threatening diseases report their palliative care needs systematically using validated tools, but unfortunately this is not happening systematically outside specialized palliative care in Denmark.³

Clearly the differences observed between diagnoses at admission may fully or partially reflect how patients are selected for referral and admission to specialized palliative care. Several studies have documented a significant symptom burden in patients with congestive heart failure, chronic obstructive pulmonary disease and chronic renal failure³⁵ and other studies have found that non-cancer patients with advanced disease had the same or a higher symptom burden than those with cancer.^{32,36,37} Thus, compared to lung cancer patients, patients with COPD had significantly worse activities of daily living and physical, social, and emotional functioning and a higher risk of anxiety/depression,³⁶ heart failure patients experienced higher anxiety levels but lower depression levels compared to cancer patients³⁷ and renal patients and cancer patients experienced similar levels of symptoms and problems.³² Therefore, our study and others underline the need to improve access to palliative care for patients with advanced non-cancer disease.

Strengths and limitations

The very large population size is a major strength in this study, which by far is the largest study to date comparing symptomatology between cancer and non-cancer patients at the start of palliative care. Also, it is a strength that we included nationwide data from all specialized palliative care services in Denmark with information from all the admitted patients who reported symptoms/problems at the start of palliative care for 6 years. It is also a strength that symptomatology data was reported by patients using the same instrument across diagnostic groups which, to our knowledge, has only been done previously in a much smaller study from the US¹⁶ and, thus, never in a European country. A limitation in the study is that we only have symptomatology data on patients admitted to palliative care and since only 2% of patients with non-cancer disease are admitted to palliative care before death in Denmark (Supplemental Table 1), we do not know if the symptomatology of the included non-cancer patients in this study is representative of all patients with advanced

non-cancer chronic diseases. Therefore, we cannot be sure that the level of palliative care needs found for non-cancer patients would change if a larger proportion of patients dying from other chronic diseases than cancer had been admitted to specialized palliative care. This is important to remember when comparing palliative care needs between patients with cancer and patients with other diagnoses. The small proportion of non-cancer patients who are referred to palliative care may be those who have the most complex symptomatology. In future research, it would be relevant to follow the development of symptoms and problems over time for patients with life-threatening non-cancer diseases, who have not been referred to specialized palliative care to gain knowledge on which patients should be referred to palliative care at which stages of the disease.

Conclusions

High prevalence and levels of several symptoms and problems were found among patients with cancer and non-cancer diseases at the start of palliative care. Overall, non-cancer patients had a higher risk of experiencing several symptoms, poor physical and emotional functioning, and low quality of life. This suggests that the access to palliative care for non-cancer patients should be improved by improving identification of palliative needs.

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Author contributions

All authors made substantial contributions to the design, analysis of data, critical revision and approved the publication, participating sufficiently to take responsibility for the content of this article.

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Ethical approval

This study was based only on registers from the Danish Palliative Care Database; therefore, it had no impact on any individuals' care and Ethics Committee approval was not required according

to Danish law. The study was conducted following the approval from the Danish Data Protection Agency (j.nr.: 2007–58-0015/local j.nr. BFH P-2021-652).

Data availability

The data utilized in this study are available through the Danish Palliative Care Database. Restrictions apply to the availability of these data.

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Supplemental material

Supplemental material for this article is available online.

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