Palliative Medicine Reports
Volume 4.1, 2023
DOI: 10.1089/pmr.2022.0068
Accepted March 13, 2023

Palliative Medicine Reports
Mary Ann Liebert, Inc. publishers

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ORIGINAL ARTICLE Open Access

Specialist Palliative Care Consultation for Patients with Nonmalignant Pulmonary Diseases: A Retrospective Study

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Abstract

Background: Few patients with chronic nonmalignant pulmonary diseases receive specialist palliative care consultation, despite their high symptom burden in end of life.

Objectives: To study palliative care decision making, survival, and hospital resource usage in patients with nonmalignant pulmonary diseases with or without a specialist palliative care consultation.

Methods: A retrospective chart review of all patients with a chronic nonmalignant pulmonary disease and a palliative care decision (palliative goal of therapy), who were treated in Tampere University Hospital, Finland, between January 1, 2018 and December 31, 2020.

Results: A total of 107 patients were included in the study, 62 (58%) had chronic obstructive pulmonary disease (COPD), and 43 (40%) interstitial lung disease (ILD). Median survival after palliative care decision was shorter in patients with ILD than in patients with COPD (59 vs. 213 days, $p = 0.004$). Involvement of a palliative care specialist in the decision making was not associated with the survival. Patients with COPD who received palliative care consultation visited less often emergency room (73% vs. 100%, $p = 0.019$) and spent fewer days in the hospital (7 vs. 18 days, $p = 0.007$) during the last year of life. When a palliative care specialist attended the decision making, the presence and opinions of the patients were recorded more often, and the patients were more frequently referred to a palliative care pathway.

Conclusions: Specialist palliative care consultation seems to enable better end-of-life care and supports shared decision making for patients with nonmalignant pulmonary diseases. Therefore, palliative care consultations should be utilized in nonmalignant pulmonary diseases preferably before the last days of life.

Keywords: chronic obstructive pulmonary disease; consultation; end-of-life care; interstitial lung disease; nonmalignant pulmonary disease; palliative care

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Introduction

The need for palliative care has been recognized not only in cancer patients but also in those with many nonmalignant diseases. Patients with chronic progressive pulmonary diseases, such as chronic obstructive pulmonary disease (COPD) or interstitial lung diseases (ILDs), have as high symptom burden in end of life as patients with lung cancer.[1–4]

Already years before death, patients with nonmalignant pulmonary diseases suffer from breathlessness, cough, fatigue, anxiety, depression, and pain, and their quality of life is often markedly decreased.[5–9]

Compared with patients with cancer, a few patients with chronic pulmonary diseases receive palliative care.[10–18] Cancer patients are also referred to palliative care earlier and their initial palliative care contact is more often an outpatient visit, whereas patients with chronic pulmonary diseases are more likely to have their first palliative care contact in the intensive care unit or during other hospitalization.[4]

Symptom-alleviating medications are less often used in patients with nonmalignant diseases, and they undergo more diagnostic tests and invasive ventilation during the last year of life compared with cancer patients.[12,13,19] Specialist palliative care may decrease the number of emergency department visits, hospitalization, and end-of-life costs, but the quality of evidence is low and the most effective ways to integrate palliative care in the care of nonmalignant pulmonary diseases remain unknown.[20]

One of the main reasons for the poor integration and late timing of palliative care in nonmalignant pulmonary diseases is the difficulty to define the need for palliative care and appropriate timing for referral to palliative care services.[18] The Finnish national palliative care guidelines and recommendations of the Ministry of Health and Welfare instruct physicians to recognize patients with a need to shift the goal of the treatment to symptom-centered palliative care by making a palliative care decision.[21,22]

Palliative care decision identifies patients with very advanced and incurable diseases when disease trajectory cannot be markedly influenced by disease-centered treatment options and the intent of the treatment is palliative. This decision is documented by the International Classification of Diseases (ICD)-10 code Z51.5 (Palliative care) in the patient records.

All physicians are recommended to make these decisions when appropriate and to consult or refer the patient to specialist palliative care services if needed. Specialist palliative care consultation services should be arranged in all secondary care hospitals in Finland and are currently available in all five university hospitals, including Tampere University Hospital.

Timely palliative care decisions and palliative care services have been shown to decrease aggressive oncologic therapies, emergency visits, and stays in acute hospitals during the end of life among cancer patients.[23,24] However, the practice of palliative care decisions and specialist consultations concerning patients with nonmalignant pulmonary diseases has not been described.

The aims of this study were to describe the timing and clinical practice of palliative care decisions in patients with nonmalignant pulmonary diseases and to explore the association of a specialist palliative care consultation on the decision-making process, survival time, and hospital resource usage.

Materials and Methods

Design

We conducted a retrospective study of all patients with a nonmalignant pulmonary disease and a palliative care decision treated in Tampere University Hospital from January 1, 2018 to December 31, 2020. Patients were followed up until death or December 31, 2021.

Approval for this study and a permission to access the patient records were obtained from the Pirkanmaa Hospital District, Tampere, Finland (R20592). According to the Finnish law and research regulations, no ethics committee approval was needed for this retrospective register-based study. This study was conducted according to national laws, regulations, and the declaration of Helsinki.

Setting

Tampere University Hospital provides secondary health care for a population of 530,000 inhabitants of the Pirkanmaa Hospital District and tertiary-level care for a population of 900,000 inhabitants. Annually, over 1500 patients with a documented palliative care decision (ICD-10 code Z51.5) are taken care of in the hospital. Palliative care decision is defined as setting the goal of care to symptom-centered palliative care aimed at maximizing quality of life in patients with very advanced diseases when survival cannot be markedly prolonged with therapy, or the patient does not prefer life-prolonging therapies.

The decision should be discussed with a patient and/or his/her closest ones (mandatory if the patient

is not able to communicate) aiming at a shared decision making and mutual understanding.

The hospital's palliative care unit offers consultations through consultation team for all the units and wards in Tampere University Hospital or through outpatient visits. Consultations are provided by physicians with a special competency in palliative medicine. In addition, nurses with special training in palliative care are routinely included in the multidisciplinary team and other professionals when needed. The palliative care unit provides about 1000 inpatient consultations and 1200 outpatient visits a year. Any clinician taking care of a patient can ask for a palliative care consultation if the patient agrees to this.

A regional palliative care pathway has been organized in collaboration with the palliative care unit and the communities of the Pirkanmaa Hospital District. The pathway includes home care teams and community hospital wards or the Pirkanmaa hospice, where patients with a palliative care decision may be admitted without needing a visit in the emergency room (ER).

All the communities have a physician and a nurse responsible for the end-of-life care. Patients need to have a palliative care decision to be included in the pathway and may then be referred to these physicians to ascertain qualified end-of-life care.

Study population/participants

Altogether, 884 patients with a diagnosis of pulmonary disease and a documented palliative care decision (ICD-10 code Z51.5) were identified from the patient records of the Tampere University Hospital. After excluding patients who had another advanced disease (e.g., cancer) as the primary reason for palliative care decision, 107 patients with chronic nonmalignant pulmonary diseases were included in this study.

Data collection

All the hospital's electronic patient records were reviewed. Collected data included age, sex, main diagnosis, living conditions, smoking status, pack-years, forced expiratory volume in one second, comorbidities, and the date of death. Patients were considered to need help in activities of daily living if they were supported by a caregiver at home (a family member or home care services) or were permanently accommodated in a nursing home or community hospital. Charlson comorbidity index was calculated for each patient.[25,26] The main diagnosis was defined as the disease that induced the need for palliative care.

For the last year of life, we recorded all ER visits and acute hospitalization days (i.e., pre-planned follow-up visits were excluded) at the Tampere University Hospital.

Intake in a palliative care pathway was reported if the patient was referred to the local physicians and nurses in the communities and was organized to have pre-planned end-of-life care by the home care team, the community hospital, or a hospice.

In addition, details of the palliative care decision were evaluated by recording the date and place of the decision, the specialty of the physician responsible for the decision, the presence of the patient and his/her closest ones, opinions of the patient and his/her closest ones on the decision, concomitant decisions to withhold therapies such as resuscitation or intensive care, and the presence of a palliative care specialist.

Data analysis

As most of the distributions were non-normal, non-parametric tests were used. The Pearson Chi-square test or Fisher's exact test was used for categorical variables and the Mann–Whitney *U* test for continuous variables. Survival estimations were made by the Kaplan–Meier method with log-rank test.

Statistical significance was set as p-value <0.05. Analyses were performed using IBM SPSS Statistics version 27.0 (IBM Corp., Armonk, NY, 2020).

Table 1. Patient Characteristics

Total number, *n*	107
Male, *n* (%)	57 (53)
Age, median years (range)	77 (60–91)
Main diagnosis, *n* (%)	
COPD	62 (58)
Interstitial lung disease	43 (40)
Other	2 (2)
Needing help with ADL, *n* (%)	90 (84)
Smoking status, *n* (%)	
Never-smoker	25 (23)
Ex-smoker	62 (58)
Current smoker	19 (18)
Unknown	1 (1)
Pack-years, median (range)	40 (2–80)
FEV_1 (% of predicted), median (range)[a]	44 (12–100)
COPD	30 (12–76)
Interstitial lung disease	65 (30–100)
Other	49 (42–56)
Long-term oxygen therapy one year before death, *n* (%)	51 (55)
Charlson comorbidity index, median (range)	6.0 (2–12)

[a]Missing value in 10 patients due to loss of data in patient records.
ADL, activities of daily living; COPD, chronic obstructive pulmonary disease; FEV_1, forced expiratory volume in one second.

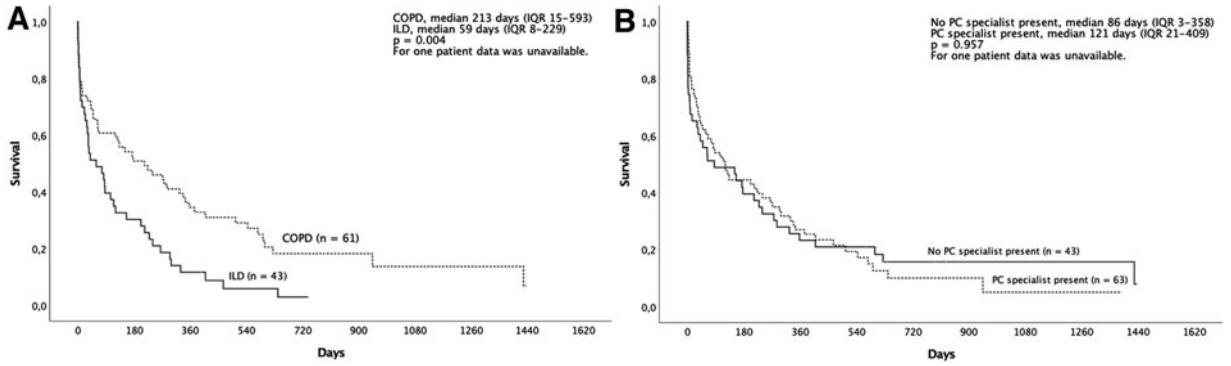

FIG. 1. Median survival times after the palliative care decision in patients with COPD or ILD **(A)** and with or without PC consultation **(B)**. COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; IQR, interquartile range; PC, palliative care.

Results

Patient characteristics are represented in Table 1. Of the 107 patients, 62 (58%) had COPD, and 43 (40%) ILD. Other diagnoses (2 patients) included obliterative bronchiolitis and chronic respiratory insufficiency caused by asthma, obesity-hypoventilation, and embolization. The median age at the time of palliative care decision was 77 years.

Until the end of follow-up, 93 (87%) patients had deceased. The median survival time from the palliative care decision was 118 days (interquartile range [IQR] 11–376). The median survival time after the palliative care decision was significantly longer in patients with COPD (213 days, IQR 15–593) than in those with ILD (59 days, IQR 8–229), (Fig. 1A), whereas the palliative care specialist's involvement in the decision-making process was not associated with the survival time (Fig. 1B).

All the patients had a do not resuscitate (DNR) order recorded. The median time from the DNR order to the palliative care decision was 255 days (IQR 59–676) and to death 479 days (IQR 179–944) in patients with COPD and 18 days (IQR 4–262) and 177 days (IQR 33–453) in patients with ILD, respectively.

Of the deceased patients, 64 (69%) achieved palliative care consultation (Table 2). During the last year of life, the proportion of patients with COPD visiting ER was significantly lower if they received palliative care consultation compared to those without consultation, and they had fewer acute hospitalization days in Tampere University Hospital (Table 2).

The proportion of the patients referred to the palliative care pathway was significantly higher among the patients with than without palliative care consultation (88% vs. 58%, $p < 0.001$). Altogether 17 (18%) patients died in Tampere University Hospital. Of the patients with palliative care consultation, 14% died in the University hospital, compared with 28% of those without a consultation ($p = 0.118$).

Details of the palliative care decisions are shown in Table 3. A palliative care specialist was present during the palliative care decision making in 59% of the cases. This proportion was significantly higher among the patients with ILD than those with COPD (72% vs. 51%,

Table 2. Patients Visiting Emergency Room and Acute Hospitalization Days in Secondary Care Hospital During the Last Year of Life in Patients With or Without Palliative Care Consultation

	Total	Palliative care consultation	No palliative care consultation	*p*
Number of patients, *n* (%)				
All	93	64 (69)	29 (31)	
COPD	51	33 (65)	18 (35)	
ILD	41	30 (73)	11 (27)	
Patients visiting ER, *n* (%)				
Less than one month before death				
All	37 (40)	24 (38)	13 (45)	*0.504*
COPD	21 (41)	13 (39)	8 (44)	*0.726*
ILD	15 (37)	10 (33)	5 (46)	*0.491*
Less than one year before death				
All	75 (81)	48 (75)	27 (93)	*0.041*
COPD	42 (82)	24 (73)	18 (100)	*0.019*
ILD	32 (78)	23 (77)	9 (82)	*1.000*
Number of days spent in hospital, median (range)				
Less than one year before death				
All	10 (0–108)	8 (0–108)	12 (0–61)	*0.209*
COPD	10 (0–93)	7 (0–93)	18 (6–61)	*0.007*
ILD	7 (0–108)	11 (0–108)	3 (0–60)	*0.210*

ER, emergency room; ILD, interstitial lung disease.

Table 3. Characteristics of Palliative Care Decisions With and Without the Presence of Palliative Care Specialist

	Total	Palliative care specialist present	No palliative care specialist present	*p*
All patients, *n* (%)	106[a]	63 (59)	43 (41)	
Age, median years (range)		76 (63–91)	78 (60–91)	*0.467*
Disease group, *n* (%)				*0.061*
COPD	61 (58)	31 (49)	30 (70)	
Interstitial lung disease	43 (41)	31 (49)	12 (28)	
Other	2 (2)	1 (2)	1 (2)	
Place of decision, *n* (%)				*0.001*
Ward	64 (60)	40 (64)	24 (56)	
Outpatient clinic	30 (28)	21 (33)	9 (21)	
Intensive care unit	2 (2)	2 (3)	0 (0)	
Other[b]	10 (9)	0 (0)	10 (23)	
Reported as present in decision making, *n* (%)				
Patient	99 (94)	63 (100)	36[c] (86)	*0.002*
Closest ones	57 (54)	40 (64)	17[c] (41)	*0.020*
Reported agreement with the decision, *n* (%)				
Patient	82 (78)	55 (87)	27[c] (64)	*0.005*
Closest ones	35 (33)	24 (38)	11[c] (26)	*0.205*

[a]For 1 patient, data were unavailable.
[b]Decisions made at palliative home care or emergency room.
[c]For 1 patient, data were unavailable.

$p = 0.029$). Most of the palliative care decisions were made at hospital wards whether a palliative care specialist was present or not.

When a palliative care specialist attended, patients and/or closest ones were more often reported to be present in the decision making. In addition, patients' agreement to the decision was reported more often if a palliative care specialist was present ($p = 0.005$). If a palliative care specialist attended, decisions to withhold therapies were made more often concomitantly with the palliative care decision, although the difference did not reach statistical significance (43% vs. 26%, $p = 0.069$).

Discussion

Based on the results of this study, consultations with a palliative care specialist were associated with increased involvement of patients and closest ones in the palliative care decision making and referrals to the palliative care pathway, whereas the consultations were not associated with decreased survival time of the patients. Palliative care consultations also seem to decrease ER visits and days spent in the hospital during the last year of life in patients with COPD. However, these effects are not clear among patients with ILD probably due to the late recognition of the need for palliative care.

In nonmalignant pulmonary diseases, receiving palliative care is associated with better symptom relief and quality of life, increased rate of advance care planning, death outside the hospital, and decreased burden from futile therapies and investigations in end of life.[3,10,18,19,27–30] The symptom burden and the need of palliative care in different nonmalignant pulmonary diseases are similar but the disease trajectory varies.[31,32] Patients with COPD may live long with advanced disease and severe breathlessness, whereas survival time is typically shorter among patients with end-stage ILD.[33]

In our study, we also found that survival time was shorter in patients with ILD compared with those with COPD even after the recognition of a need for palliative care decision. Our results are in line with previous studies showing that referral to palliative care and end-of-life care decisions occur late in ILD.[1,34]

This late integration of palliative care in ILD may, at least partly, be due to the fact that although similar signs (e.g., severe dyspnea and functional impairment) of advanced disease are present in all nonmalignant lung diseases, they reflect poorer survival in ILD compared with in COPD, for example. Our results support the current recommendations, that palliative care should be integrated early into disease-modifying treatment options especially in ILD to allow well-timed advance care planning and pre-planned arrangements for end-of-life care.[35]

There is limited evidence on the reduction of hospital resource usage if patients receive specialist palliative care. Some studies show a remarkable decrease in both ER visits and hospital deaths in both COPD and ILD in integrated hospital-based palliative care models.[28,29] In this study, specialist palliative care consultation was associated with less use of hospital resources during the last year of life in patients with COPD but not in those with ILD.

This finding might be explained by the late recognition of the need of palliative care in ILD as discussed earlier. Nevertheless, we did not find a statistically significant difference in resource usage one month before death in either COPD or in ILD group, probably due to a small sample size. Patients were more often referred to a palliative care pathway if they received palliative care consultation.

This pathway offers pre-planned arrangements for end-of-life care, facilitating easy access to home care services and to end-of-life care in a community hospital ward or a hospice for patients with a palliative care decision. This probably was the major factor explaining

the decreased usage of hospital resources through palliative care consultation in our study and highlights the importance of collaboration between in-hospital palliative care teams and regional palliative care providers in the area.

Discussing very advanced diseases and changing the goal of therapy from cure to care (palliative care decision) are delicate issues for patients and their closest ones. When talking about their illness, patients and their closest ones expect honesty, openness, and clarity.[36,37] In this study, we found aspects reflecting more patient-centered shared decision making when a palliative care specialist was involved in the palliative care decision since patients and their closest ones were reported to be present during the discussion more often and patients' opinion on the decision was also reported more frequently. Similar to a study conducted by Bischoff et al., we found that including a palliative care consultation increased the amount of advance care planning notes and reported decisions to withhold futile therapies.[27]

There is controversial knowledge about the optimal timing of the discussions on goals of care and advance care planning regarding a patient's perspective. Too early discussions may not feel relevant for the patient and there might be hesitance to engage in advance care planning[5,38] but, on the other hand, in a recent qualitative study, patients expressed willingness to learn about end-of-life regardless of the severity of their disease.[36]

Further, clinicians may also feel uncertain about the optimal timing of these discussions.[39] In this study, we found that the involvement of a palliative care specialist in the decision-making process is not associated with impaired survival time. This knowledge could encourage pulmonologists to ask for palliative care consultations without a fear of limiting patients' prognosis by, so to say, "giving up" too early.

In patients with nonmalignant pulmonary diseases, palliative care can be integrated to support the physical, emotional, and spiritual well-being of the patients alongside the usual management of the disease itself. Early palliative care and advance care planning could start as early as at the time of the diagnosis of a serious respiratory illness.[35]

This kind of early integration requires collaboration of pulmonary and palliative care clinics to find the best practices to enable consultations. For patients with ILD, a palliative care specialist attended more frequently in the decision making. Shifting of the treatment toward palliative care in ILD may be relatively sudden and occur even during an acute exacerbation with very limited curative treatment options, poor prognosis, and severe symptoms, which may necessitate specialist palliative care intervention from both the clinicians' and patients' perspectives.

Nevertheless, patients with COPD also seem to benefit from a specialist palliative care consultation, and therefore more systematic and early enough consultations in both disease groups are called for.

Strengths and limitations of the study

This was a real-life study and although there are some limitations, we were able to provide information useful for clinicians taking care of patients with chronic nonmalignant pulmonary diseases. It was possible to retrieve information relevant to this study from the patient records retrospectively.

A relatively small sample size limits the statistical power, which may not have been sufficient to detect weak associations in statistical analyses. Only Tampere University Hospital patient records were evaluated, so we lacked information on the place of death and health care resource usage outside the University Hospital. This is a single-center study from Finland; therefore, the generalizability of the results to other nations and health care systems must be done with caution.

Further prospective studies are needed, which should concentrate on studying these patients through all health care system levels to make more accurate estimations on the effect of a specialist palliative care on resource usage. Qualitative studies are also needed to assess the possible benefits regarding patients' and their closest one's perspectives.

Conclusions

Our findings suggest that in nonmalignant pulmonary diseases a specialist palliative care consultation allows patients and their closest ones to be better involved in the decision making and leads them more often into a palliative care pathway. Specialist palliative care consultations seem to decrease hospital resource usage during the last year of life, at least in COPD.

The benefits of palliative care consultation in ILD may be impaired by the late recognition of the need of palliative care. Timely advance care planning and integration of specialist palliative consultations to the care of all nonmalignant pulmonary diseases are called for.

Authors' Contributions

Conception and study design was done by all the authors. Data collection was made by H.P. Data analysis was carried out by H.P., H.R., and R.P.P. All the authors participated in the writing of the article and approved the final manuscript.

Funding Information

No funding was applied for this study.

Author Disclosure Statement

The authors declare that there are no conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Cite this article as: Pihlaja H, Rantala H, Leivo-Korpela S, Lehtimäki L, Lehto JT, Piili RP (2023) Specialist palliative care consultation for patients with nonmalignant pulmonary diseases: a retrospective study, *Palliative Medicine Reports* 4:1, 108–115, DOI: 10.1089/pmr.2022.0068.

Abbreviations Used

ADL = activities of daily living
COPD = chronic obstructive pulmonary disease
DNR = do not resuscitate
ER = emergency room
FEV_1 = forced expiratory volume in one second.
ICD = International Classification of Diseases
ILD = interstitial lung disease
IQR = interquartile range
PC = palliative care

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