



Original Research

The use of specialist palliative care services differs in chronic obstructive pulmonary disease and interstitial lung disease: A national cohort study

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ABSTRACT

Background: High symptom burden and psychosocial needs in chronic obstructive pulmonary disease (COPD) and interstitial lung disease (ILD) warrant palliative care. We assessed the use of specialist palliative care (SPC) and its association with the use of emergency department (ED) and hospital inpatient days in COPD and ILD.

Methods: A retrospective cohort study of all Finnish decedents who died of COPD ($n = 1189$) or ILD ($n = 382$) in 2019. Data was gathered from the registries of the Finnish Institute of Health and Welfare. Demographics, the use of SPC, the use of ED, and hospital inpatient days during the last six months of life were evaluated.

Results: During the last six months of life, ILD patients used more ED (92 % vs. 84 %, $p < 0.001$) and spent more time at the hospital (median of 19 vs. 12 days, $p < 0.001$) compared to COPD. Overall, 12 % and 8 % of the ILD and COPD patients had contact with SPC, respectively ($p = 0.012$). During the last month of life, SPC reduced the use of ED both in COPD (57 % vs. 68 %, $p = 0.036$) and ILD (58 % vs. 74 %, $p = 0.021$), as well as the number of days spent in secondary care hospitals in ILD (median of 0 vs. 2 days, $p = 0.011$). Also in multivariate analysis, SPC reduced the use of ED. Most patients (72 %) died in a hospital.

Conclusions: ILD patients received more SPC than COPD patients, yet the numbers were low in both patient groups. Using acute hospital resources was common during the last months of life, but SPC reduced this.

1. Introduction

There is an increasing consensus on the need for palliative care (PC) in patients with chronic obstructive pulmonary disease (COPD) or interstitial lung disease (ILD), yet few patients with these life-limiting illnesses receive PC services [1–9]. Further, the importance of integrated PC may occasionally remain underrepresented when discussing the treatment of serious respiratory illness [10].

There are challenges in defining the right time for PC referral, and this may impair the access of patients with advanced COPD or ILD to PC services [11]. The lack of high-quality PC in patients with end-stage nonmalignant pulmonary diseases leads to poor symptom control and lower quality of life [4,12–14]. In addition to breathlessness, depression,

anxiety, social isolation, and low spiritual well-being enhance the multidimensional suffering related to these diseases [15,16]. Also, the distress among patients' formal or informal caregivers may be overwhelming [17]. Latest guidelines suggest integration of PC to disease-centered treatment, which may especially improve patients' quality of life by addressing physical, psychological, and spiritual needs, and finally ensure a dignified death [2,15,18,19]. Skilled communication with patients and their caregivers is an essential aspect of care, which aims to increase their prognostic awareness and face their major concerns related to physical symptoms, but importantly also to loss of autonomy, agency, and functional independence [20].

Moreover, regardless of the patient's preferred place of death, they mostly die inadvertently in a hospital without proper planning for the

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end-of-life (EOL) [5,21]. In addition to patient-centered outcomes, it's possible that PC can lower healthcare costs in patients with nonmalignant pulmonary diseases, but the evidence is controversial [22].

Though guidelines support early recognition and referral to PC services in patients with advanced nonmalignant pulmonary diseases, we have little knowledge of how these recommendations are accomplished [3,23]. Also, it remains unsure if PC can reduce the use of acute care resources during EOL in patients with COPD or ILD.

Patients with COPD or ILD are usually studied in the context of PC as a combined group of nonmalignant pulmonary diseases, although they may have different disease trajectories and PC needs. Therefore, there is a need to sort out potential differences and pitfalls in the clinical practices between these two patient groups in the palliative phase of the illness to offer appropriate PC for them.

This population-level study aimed to describe the prevalence and timing of the use of specialist palliative care (SPC) services in patients with COPD or ILD and to explore the association of SPC with the use of emergency department (ED) and hospitalization in these patient groups.

2. Materials and methods

2.1. Study cohort

This is a study cohort covering all ≥ 18 -year-olds who died of COPD or ILD in Finland in 2019. Patients were identified from the Causes of Death Register (Statistics Finland) based on the International Statistical Classification of Diseases (ICD-10) codes for emphysema, other chronic obstructive pulmonary diseases, or other interstitial pulmonary diseases (J43, J44, J84) as the underlying cause of death [24]. Altogether, 1571 patients were included in the study. The study was conducted according to the STROBE reporting guidelines [25].

2.2. Utilization of healthcare services

Data from national Care Registers and Kanta Services were used to provide information on socio-demographics and utilization of healthcare resources. The Care Register and Kanta Services are supplied nationally by the Finnish Institute of Health and Welfare, and these registries are mandatory for all healthcare providers. This nationwide data includes outpatient clinic visits and hospitalizations in primary and secondary (including tertiary) health care, and contacts to emergency departments. The Care Register data was linked to a list of healthcare unit codes to identify the utilization of different services including SPC services. The data is available from the beginning of 2018 until the end of 2019. All the data extracted from registries were linked using the personal identification number for each patient, which was subsequently replaced with a research number to pseudonymize the data.

2.3. Determination of specialist palliative care services

In Finland, palliative care can be offered at a general or specialist (SPC) level. SPC services include specialist outpatient clinics, inpatient wards (including hospice), hospitals at home, and inpatient consultative palliative care teams. SPC services are provided by multidisciplinary teams including physicians with a special competency in palliative medicine and other professionals with special education in palliative care.

2.4. Determination of palliative care decision

In Finland, the ICD-10 code Z51.5 Palliative care is used to identify patients with very advanced diseases and a need to shift the goal of care into palliative intent, when survival cannot be markedly prolonged with disease-centered therapies, or the patient does not prefer them [26]. The first occurrence of the Z51.5 diagnosis code is referred to in this article as making a palliative care decision. All clinicians are recommended to

make these decisions together with the patient and his/her closest ones and to consult SPC services when needed [26,27]. The Z51.5 code was identified from the Care Register data. The use of this diagnosis code was not systematic across the country during the study period.

2.5. Place of death and degree of urbanization

The place of death was determined from the 2019 Causes of Death Register data and categorized as home (private housing), long-term care facility, or hospital (including primary and secondary hospitals, and SPC wards). Death at an SPC ward was recorded if the patient was taken care of in these units on the day of death. Municipalities were classified into urban, semi-urban, and rural as defined by the Statistics Finland Statistical grouping of municipalities [28].

2.6. Ethical statement

This study was conducted in collaboration with the Finnish Institute for Health and Welfare (THL) as part of the Project on Quality Information on Palliative Care and End-of-life Care. Approval for the study was obtained from THL (Dnro THL/908/6.02.00/2021). A separate ethical approval is not required. The Act on Secondary Use of Health and Social Data (552/2019) was enforced in Finland in May 2019 and provides uniform conditions for the secure use of client (patient) data compiled from service activities within health care and social services for purposes permitted by law, such as research, development activities, and management. The study was conducted according to national laws, regulations, and the Declaration of Helsinki.

2.7. Statistical analysis

Given that the distributions were nonnormal, the nonparametric Mann–Whitney *U* test was used for continuous variables. The Pearson chi-square test or Fisher's exact test was used for categorical variables when appropriate. The T-test was used to compare the mean age between the study groups. A logistic regression model (enter-model) was used to analyze the relationship between age, gender, diagnosis, contact with SPC and the use of ED during the last month of life.

Statistical significance was set as a *p*-value less than 0.05. Analyses were performed using IBM SPSS Statistics version 29.0.0.0 (IBM Corp. Armonk, NY, 2020).

3. Results

Of the patients, 1189 (76 %) had COPD and 382 (24 %) ILD. [Table 1](#) presents an overview of patient characteristics. Most patients (72 %)

Table 1
Patient characteristics.

	Total		COPD		ILD		<i>p</i> -value
Number of patients, n (%)	1571	(100)	1189	(76)	382	(24)	
Female, n (%)	559	(36)	411	(35)	148	(39)	0.138
Age at death, mean years (SD)	78	(8.9)	77	(9)	81	(8.3)	<0.001
Place of death, n (%)							<0.001
Home	289	(18)	240	(20)	49	(13)	
Long term care	158	(10)	139	(12)	19	(5)	
Hospital	1124	(72)	810	(68)	314	(82)	
Death at SPC ward, n (%)	26	(1.7)	20	(1.7)	6	(1.6)	0.882
Palliative care decision, n (%)	172	(11)	97	(8)	75	(20)	<0.001

COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; SD, standard deviation.

SPC, specialist palliative care.

died in a hospital, and this was especially true among the patients with ILD. Twenty-six (1.7 %) patients died in an SPC ward. Of those who died at home, ten (3.5 %) had contact with a hospital at home two weeks before death.

Patients using the ED and hospital inpatient days during the last 6 months of life among patients with COPD or ILD are shown in Table 2. Contacts to the ED were common in both patient groups, but the proportion of ILD patients using the ED was even higher compared to the patients with COPD. Even during the last two weeks of life, 54 % and 55 % of the patients with COPD or ILD used the ED ($p = 0.807$). ILD patients spent more time in the hospital during the last 6 months before death compared to COPD patients, although this difference was statistically significant only regarding hospitalization at secondary care.

The prevalence and timing of the first SPC contacts and PC decisions are shown in Fig. 1a and 1b. Overall, 12 % and 8 % of the patients with ILD and COPD had contact with SPC services, respectively ($p = 0.012$). Particularly during the last month of life, patients with ILD had more contact with SPC services compared to patients with COPD (5.2 % vs. 2.3 %, $p = 0.003$). The median time from the first SPC contact to death was 56 days (IQR 18–212) in patients with ILD and 148 days (IQR 22–361) in patients with COPD ($p = 0.080$). PC decisions were recorded more often for patients with ILD than for patients with COPD (19 % vs. 8 %, $p < 0.001$). Of the PC decisions, 53 % were made during the last month of life (56 % in COPD and 49 % in ILD). The median time from PC decision to death was 31 days (IQR 10–70) in patients with ILD and 23 days (IQR 8–96) in patients with COPD ($p = 0.799$).

Table 3 compares the utilization of different SPC services between patients with COPD or ILD. A higher percentage of patients with ILD than those with COPD had contact with PC outpatient clinics and received hospital at home care, while there was no significant difference in the proportion of patients taken care of at the SPC wards between the disease groups.

The association of SPC with the use of ED and hospital inpatient days is presented in Table 4. Contact with SPC was significantly associated with a lower percentage of patients using the ED during the last month of life in both disease groups. For patients with ILD, this association was also significant 3 months before death. Similarly, patients with a PC decision recorded before the last month of life visited the ED more seldom during the last month and 3 months of life compared to patients with no PC decision (38 % vs. 70 %, $p < 0.001$, and 69 % vs. 82 %, $p = 0.003$, respectively). Inpatient days at secondary care hospitals during the last month of life were significantly reduced among patients with ILD who had contact with SPC services. In contrast, SPC contact did not decrease inpatient days at secondary care hospitals among patients with

COPD. By multivariate analysis, gender, diagnosis and contact with SPC were found as independent factors explaining the use of ED during the last month of life (Table 5).

4. Discussion

In this study, only a few patients with COPD or ILD received SPC and most died in a hospital. The first SPC contact frequently occurred late in the disease trajectory, and early palliative care seemed to be rare. However, in patients with ILD contacts to SPC were more common than in patients with COPD. The use of acute healthcare services was common during EOL, but SPC seemed to reduce the use of ED in both patient groups and hospitalization in ILD during the last month of life.

Patients with COPD or ILD usually suffer significant symptoms already years before death, including breathlessness, cough, fatigue, anxiety, depression, and pain, and it has been recognized that receipt of PC can reduce this burden [12,29–31]. In addition to better symptom control and improved quality of life, PC also offers comprehensive support to patients' formal or informal caregivers and helps patients and their closest ones to cope with the illness in everyday life [32,33]. Also, spiritual care and building patients' prognostic awareness alongside with disease-centered treatment are essential components of PC, which can positively affect patients' dignity and help in respectful shared decision-making discussions concerning delicate issues, such as EOL preferences [19,20]. Nevertheless, our results are in line with previous studies showing that a minority of patients with nonmalignant pulmonary diseases receive PC [4–9]. Still, in this study, the need for PC seemed to be recognized more often in patients with ILD than in patients with COPD. Further studies are needed to sort out the reasons behind this difference, but we suggest that triggers for poor prognosis and approaching EOL could be more easily recognized in ILD than in COPD. In addition, patients with ILD are probably more often followed up and treated at secondary or tertiary care hospitals where SPC services are better available compared to primary care, where patients with COPD are more likely taken care of.

We also found that the first SPC contact of patients with COPD or ILD occurred mostly during the last month of life, and most PC decisions were recorded just before death. Thus, early integration of PC appeared to be rare. In both patient groups, there were also SPC contacts six months before death, but some of them may be hospital at home contacts primarily due to other indications than PC, such as treatment of infections. Altogether, the referrals to SPC were commonly made rather late considering all the potential benefits that SPC services can offer to patients with COPD or ILD. Lack of consensus about referral criteria to PC services in patients with COPD or ILD has been recently discussed as a major barrier to receiving PC [1,3]. A review by Philip et al. summarized the current practice of referral criteria to PC in patients with nonmalignant pulmonary diseases and found that clinicians evaluate a wide range of disease-centered symptoms but also psychosocial and hospital use-related factors while determining the need for PC [11]. Also, the misconception of PC being synonymous with EOL care can prevent early PC, and pulmonary clinicians may be reluctant to the use of certain therapies in PC such as opioids or benzodiazepines [34]. These organizational and clinician-related factors could explain the low number and late timing of SPC contacts in our study.

We also assessed the use of acute health care resources during the last six months of life and found that patients with COPD or ILD were hospitalized frequently during EOL, and more than half of the patients used the ED even during the last two weeks of life. Patients with ILD were more often hospitalized in secondary care, and they seemed to have even more ED contacts compared to patients with COPD. This substantial consumption of acute healthcare services near death in patients with COPD or ILD has been described also in previous studies [35,36]. Yet, to our knowledge, this is the first study that presents differences between patients with COPD or ILD. Based on the results of this study, SPC could reduce hospitalizations in patients with ILD, since contact with SPC was

Table 2

Patients using the emergency department and hospital inpatient days during the last 6 months of life.

	All	COPD	ILD	<i>p</i> -value
Patients using the ED, n (%)				
<1 month	1072 (68)	796 (67)	276 (72)	0.053
<3 months	1286 (82)	956 (80)	330 (86)	0.008
<6 months	1356 (86)	1004 (84)	352 (92)	<0.001
Inpatient days, median (IQR)				
Secondary care				
<1 month	0 (0–6)	0 (0–5)	2 (0–8)	<0.001
<3 months	2 (0–10)	2 (0–9)	6 (0–13)	<0.001
<6 months	4 (0–13)	3 (0–12)	7 (1–17)	<0.001
Primary care				
<1 month	0 (0–8)	0 (0–8)	0 (0–10)	0.101
<3 months	1 (0–15)	0 (0–14)	2 (0–18)	0.184
<6 months	3 (0–21)	2 (0–20)	4 (0–23)	0.444
All				
<1 month	6 (0–17)	5 (0–16)	9 (1–21)	<0.001
<3 months	10 (1–29)	8 (0–27)	13 (4–31)	<0.001
<6 months	14 (3–36)	12 (2–36)	19 (6–37)	<0.001

ED, emergency department; COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; IQR, interquartile range.

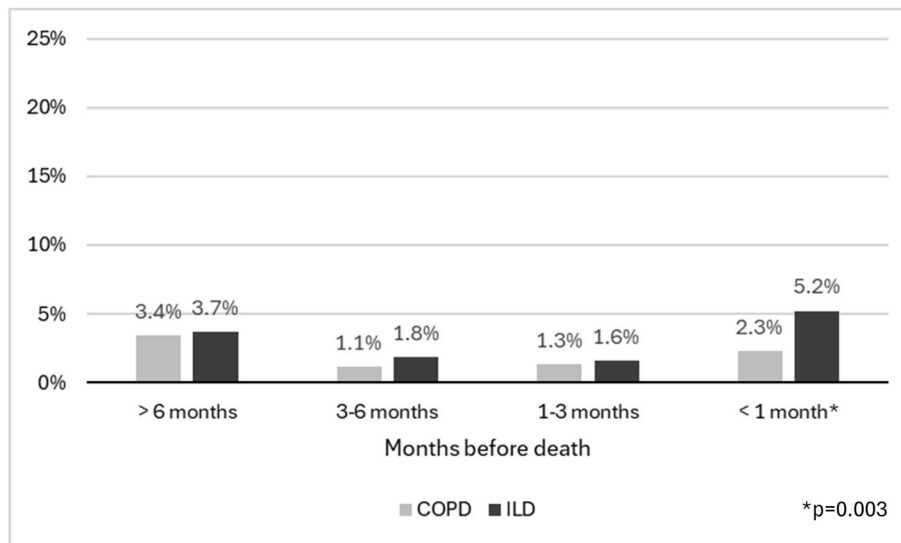


Fig. 1a. The percentage of patients having the first contact with specialist palliative care at different time intervals before death.

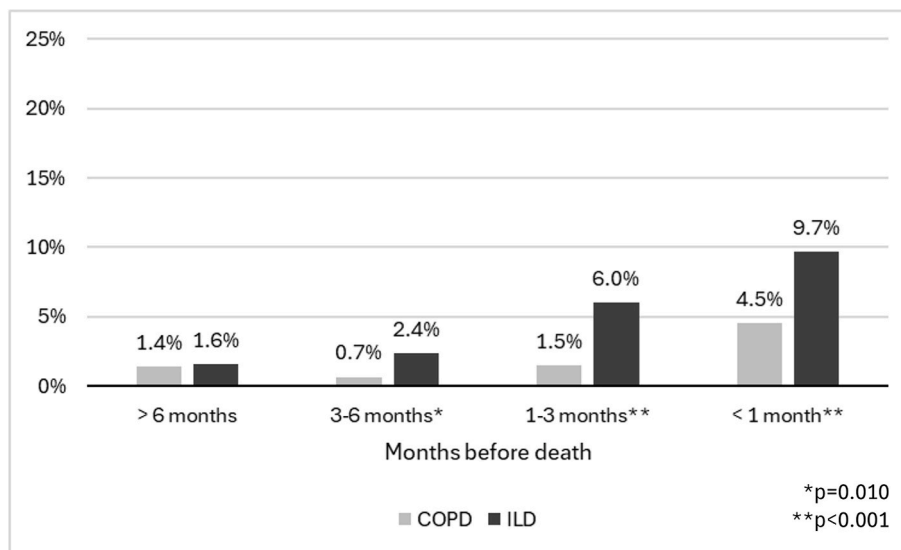


Fig. 1b. The percentage of patients with palliative care decisions made at different time intervals before death.

Table 3
Utilization of specialist palliative care services.

	All	COPD	ILD	p-value
SPC contact, total, n (%)	143 (9)	96 (8)	47 (12)	0.012
Contact to PC outpatient clinic, n (%)				
<1 month	22 (1.4)	11 (0.9)	11 (2.9)	0.005
<3 months	28 (1.8)	15 (1.3)	13 (3.4)	0.006
<6 months	30 (1.9)	17 (1.4)	13 (3.4)	0.014
Inpatient care at SPC ward, n (%)				
<1 month	35 (2.2)	25 (2.1)	10 (2.6)	0.553
<3 months	36 (2.3)	26 (2.2)	10 (2.6)	0.624
<6 months	39 (2.5)	28 (2.4)	11 (2.9)	0.566
Hospital at home care, n (%)				
<1 month	61 (3.9)	36 (3.0)	25 (6.5)	0.002
<3 months	73 (4.6)	46 (3.9)	27 (7.1)	0.010
<6 months	82 (5.2)	51 (4.3)	31 (8.1)	0.003

SPC, specialist palliative care; COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; PC, palliative care.

associated with fewer inpatient days at secondary care hospitals. Also, SPC decreased the use of ED during the last three months of life in ILD. These results are in line with previous studies suggesting that PC can diminish the use of acute healthcare resources in patients with ILD [21]. Therefore, integrating PC might be valuable in reducing the use of ED and hospitalization at secondary care months before death, but this would require more early referrals.

There was also a significant reduction in the number of patients using the ED during the last month of life in patients with COPD who had contact with SPC. Previous studies of patients with COPD receiving PC and their use of acute healthcare resources have been controversial [6, 37]. In a Belgian cohort study, palliative home care seemed to reduce ED visits and hospitalization during the last month of life, whereas in a large Canadian cohort study, the receipt of early PC in a variety of care settings was not associated with reduced use of acute healthcare resources [37]. We found similar results concerning the rate of hospitalization as did McLagan et al. in a Canadian study, i.e., the receipt of SPC did not reduce hospitalization in patients with COPD [37]. The need for hospitalization in COPD seems to be common not only in traditional disease-centered treatment but also during palliative and EOL care.

Table 4

The association of specialist palliative care services with the use of emergency department and hospital inpatient days.

	COPD		<i>p</i> -value	ILD		<i>p</i> -value
	SPC +	SPC -		SPC +	SPC -	
Total, n (%)	96 (8)	1093 (92)		47 (12)	335 (88)	
Patients using the ED, all, n (%)						
<1 month	55 (57)	741 (68)	0.036	28 (58)	248 (74)	0.021
<3 months	79 (82)	877 (80)	0.627	36 (76)	294 (88)	0.014
<6 months	83 (87)	921 (84)	0.569	44 (92)	308 (92)	0.895
Inpatient days, median (IQR)						
Secondary care						
<1 month	0 (0–4)	0 (0–5)	0.471	0 (0–4)	2 (0–9)	0.011
<3 months	4 (0–10)	2 (0–8)	0.369	4 (0–8)	6 (0–14)	0.221
<6 months	6 (0–14)	3 (0–12)	0.104	6 (0–14)	7 (1–17)	0.417
Primary care hospital						
<1 month	0 (0–4)	0 (0–8)	0.171	0 (0–7)	0 (0–9)	0.975
<3 months	0 (0–12)	0 (0–14)	0.748	1 (0–13)	1 (0–18)	0.964
<6 months	3 (0–18)	2 (0–20)	0.804	3 (0–23)	4 (0–21)	0.853
All						
<1 month	4 (0–11)	5 (0–16)	0.233	4 (0–17)	9 (1–21)	0.072
<3 months	9 (0.3–25)	8 (0–26)	0.641	11 (4–31)	13 (5–31)	0.514
<6 months	11 (2–40)	12 (2–34)	0.629	15 (4–35)	18 (7–37)	0.892

SPC, specialist palliative care; ED, emergency department; COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; IQR, interquartile range.

Table 5

Different background factors explaining the use of emergency department during the last month of life in logistic regression analysis.

	n	OR	(95 % CI)	<i>p</i> -value
Age at death	1571	0.992	(0.980–1.004)	0.208
Gender				0.010
Female	559	ref.		
Male	1012	1.337	(1.072–1.667)	
Diagnosis				0.017
COPD	1189	ref.		
ILD	382	1.376	(1.060–1.787)	
Contact with SPC				0.006
Yes	143	ref.		
No	1248	1.647	(1.156–2.345)	

OR, odds ratio; COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; SPC, specialist palliative care.

Perhaps more tailored palliative home care services could be the most effective way to reduce the need for hospitalization in patients with COPD. Further studies are needed to sort out the best practices for delivering PC to these fragile patients.

In this study, most patients with COPD or ILD died in a hospital, while under 2 % of the patients in both groups died in an SPC ward or hospice. Of those who died at home, only 3.5 % had contact with a hospital at home during the last two weeks of life. Therefore, only a minority of the patients received SPC just before death, and home deaths seemed to be rarely pre-planned and organized together with PC professionals. Similar numbers on the place of death have been reported in previous studies in patients with COPD or ILD, and evidence supports that delivering PC to patients can increase the number of home or hospice deaths [13,33,38,39]. Archibald et al. have demonstrated, that an integrated PC approach throughout the disease trajectory in patients with ILD can raise the number of home or hospice deaths even up to 62 %, but this requires early initiation of PC, advance care planning discussions, symptom self-management, caregiver support, and collaboration with health home care providers [40]. Thus, we suggest that the late recognition of the need for PC might have induced the lack of pre-planned SPC ward, hospice, and home deaths in our study.

Finally, organizing PC services for patients with nonmalignant pulmonary diseases should be thoroughly considered, since the best practices of PC may differ from those we have learned when taking care of cancer patients [41]. This is true, particularly in patients with COPD, whose survival in the PC phase of the illness is usually longer compared to patients with ILD [42]. The longer PC phase requires more resources

to follow up patients until death. Also, an unpredictable disease trajectory challenges EOL care both in patients with COPD or ILD since recovery after worsening of the symptoms in an exacerbation is possible, and the traditional hospice model may be insufficient [41]. Previous studies on patients with nonmalignant pulmonary diseases seem to support integrative models of PC, where the intensity of PC can be increased over time, and balancing between the goals of recovery and EOL care during an exacerbation could be fluently accomplished [1]. We suggest that this integration could be organized more frequently with palliative hospitals at home to provide patients with easy-access help without delays when needed and also to support caregivers more comprehensively. Prescheduled visits to PC outpatient clinics could also be considered more often, but the fragility of the patient and their willingness to leave home for burdensome visits should be taken into account individually when planning the most appropriate way to organize follow-up. Moreover, patients with COPD or ILD may suffer problematic symptoms during EOL, such as refractory dyspnea [43]. The treatment of refractory dyspnea may require special equipment and treatment strategies, such as using noninvasive ventilation or high-flow nasal therapy with comfort-only approach, or palliative sedation [44, 45]. To be able to offer adequate symptom control equally to patients dying of COPD or ILD, we should, in the future, assess best practices for delivering high-quality PC and promote the acceptability of SPC services. Also, emphasizing the need for cooperation between primary, pulmonary, and PC clinicians is important in taking care of this large and diverse group of patients.

4.1. Strengths and limitations

This study has several strengths. The data of this study are based on national registries, which are mandatory at all healthcare levels. Also, the data of these registries are partly formed automatically within patient contacts. Therefore, the data can be considered comprehensive and high-level.

We evaluated the recognition of the need for PC by using both contacts to SPC and the occurrence of palliative care decisions. The results based on using these two different parameters were similar, which adds to the reliability of the results. However, using the Z51.5 diagnosis code was not systematic during the study period. Therefore, the proportion of patients with a palliative goal of therapy may be underestimated in this data.

As a limitation, we were not able to sort out indications for hospital at home visits. Although SPC at home is arranged by hospitals at home in

Finland, there may be some other visits due to other treatment indications than PC such as treatment of infections. Also, regarding specialist outpatient contacts, we were not able to sort out outpatient visits from PC consultation team evaluations during hospitalization. The number of patients using SPC was small, and we were not able to sort out the best practices for delivering SPC, which should be an aim for future studies.

Since this is a national study of Finnish population, the generalizability of the results to other nations must be done with caution.

5. Conclusions

Few patients with COPD or ILD receive SPC, and particularly early integration of SPC is rare. The need for PC seems to be more often recognized in patients with ILD than in patients with COPD but occurs late in the disease trajectory. Using acute health care resources is common in both patient groups during EOL but contact with SPC may reduce this. Future studies should explore how to promote referrals to SPC services earlier in the disease trajectories, and which modalities of SPC are the most appropriate and effective for patients with nonmalignant pulmonary diseases.

CRedit authorship contribution statement

Hanna Pihlaja: Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Reetta P. Piili:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Mikko Nuutinen:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Tiina Saarto:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Timo Carpen:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Juho T. Lehto:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization.

Data availability statement

The data that support the findings of this study are available from the Finnish Institute for Health and Welfare, but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data permits can be requested from the Finnish Social and Health Data Permit Authority, Findata (info@findata.fi).

Ethics approval

This study was conducted in collaboration with the Finnish Institute for Health and Welfare (THL) as part of the Project on Quality Information on Palliative Care and End-of-life Care. Approval for the study was obtained from THL (Dnro THL/908/6.02.00/2021). A separate ethical approval is not required. The study was conducted according to national laws, regulations, and the Declaration of Helsinki.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Hanna Pihlaja reports financial support was provided by The Tampere Tuberculosis Foundation. Tiina Saarto and Timo Carpen reports

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Not applicable.

Glossary

COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; SPC, specialist palliative care; PC, palliative care; EOL, end of life; ED, emergency department.

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