Palliative care for interstitial lung disease: Nationwide survey of pulmonary specialists

ORIGINAL ARTICLE

TITLE: Palliative care for interstitial lung disease: Nationwide survey of pulmonary specialists

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Summary at a glance

Pulmonary specialists experienced greater difficulty, including ILD-specific barriers, in providing palliative care for patients with ILD compared to those with lung cancer. The timing of end-of-life communication was later than the physician-perceived ideal timing in ILD. Multifaceted clinical studies are needed to develop optimal palliative care for patients with ILD.

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ABSTRACT

Background and objective:

Interstitial lung disease (ILD) is progressive with high symptom burdens and poor prognosis. Patients with ILD need optimal palliative care to maintain their quality of life, however, few nationwide surveys have addressed palliative care for ILD.

Methods:

A nationwide, cross-sectional survey was conducted. Questionnaires were sent by mail to pulmonary specialists certified by the Japanese Respiratory Society (n = 3,423). The current practices of PC for ILD, end-of-life communication, referral to a PC team, barriers to PC for ILD, and comparison of PC between ILD and lung cancer (LC).

Results:

1,332 (38.9%) participants completed the questionnaire, and the data of 1,023 participants who had cared for ILD patients in the last year were analyzed. Most participants reported that ILD patients often or always complained of dyspnea and cough, but only 25% had referred them to a PC team. The timing of end-of-life communication tended to be later than physician-perceived ideal timing. The participants experienced significantly greater difficulty in symptomatic relief and decision-making in PC for ILD compared to LC. Prescription of opioids for dyspnea was less frequent for ILD than for LC. ILD-specific barriers in PC included an 'inability to predict prognosis', 'lack of established treatments for dyspnea', 'shortage of psychological and social support', and 'difficulty for patients/families to accept the disease's poor prognosis'.

Conclusion:

Pulmonary specialists experienced more difficulty in providing PC for ILD compared to LC and reported considerable ILD-specific barriers in PC. Multifaceted clinical studies are needed to develop optimal PC for ILD.

Running Title: Palliative care for ILD

Keywords: dyspnea; end-of-life communication; interstitial lung disease; palliative care; symptom relief

Introduction

Interstitial lung disease (ILD) is a group of diseases that cause inflammation and fibrosis in the interstitium of the lungs. ILD often presents with progressive clinical courses with severe clinical manifestations. Especially, advanced fibrosing ILDs, such as idiopathic pulmonary fibrosis (IPF) and progressive pulmonary fibrosis, are progressive and incurable with poor prognosis and high symptom burden[1], even though appropriate pharmacotherapy is provided[2-4]. Therefore, patients with ILD need not only a timely diagnosis and treatment access, but also adequate symptoms management to maintain their quality of life (QOL), including during end-of life care.

The importance of palliative care for patients with non-malignant lung diseases is recognized[5,6]. Patients with ILD often experience severe cough, dyspnea and psychophysical symptoms during their clinical courses[7,8], which are strongly related to QOL. Therefore, optimal symptom management and palliative care should be considered as the disease progresses[9,10]. Previous studies have demonstrated the needs of palliative care for patients with fibrotic ILD and their caregivers[11,12]. However, patients with ILD had poorer access to specialized palliative care and a lower quality of dying and death in comparison to patients with lung cancer[13], suggesting that palliative care and end-of-life care are not currently sufficient for this patient population.

Despite the urgent need to improve current practices of palliative care for patients with ILD, few nationwide surveys have addressed palliative care for ILD[7], including management of dyspnea[14]. Here, we conducted a nationwide survey of pulmonary specialists certified by the Japanese Respiratory Society (JRS), the largest and authorized scientific academy of pulmonology in Japan. The research aims are to clarify physicians' perceptions of palliative care for patients with ILD and to determine the barriers and difficulties they face in providing optimal palliative care. The findings will be useful as a foundation for formulating strategies for improving palliative care for patients with ILD.

Methods

Participant recruitment

This was a nationwide, cross-sectional survey undertaken by the Diffuse Lung Diseases Research Group in Japan. We randomly identified half of all the pulmonary physicians (n = 3,423) certified by JRS, and sent questionnaires by mail in December 2020. The responses to the questionnaire were voluntary, and indicative of consent to participate. This study was an anonymous, cross-sectional survey of pulmonary physicians and approval from the ethics committee was waived. Full details of the Methods are available in the online supplement.

Questionnaire development and measurement outcomes

The questionnaire was developed based on a review of the literature and our previous preliminary research[15-20]. The questionnaire items asked about (1) current practices of palliative care for patients with ILD; (2) optimal and actual timing of end-of-life communication between patients with ILD and attending physicians; (3) comparison of palliative care for ILD and lung cancer; and (4) physician-perceived barriers and difficulties in providing palliative care for patients with ILD. The participants rated their agreement with each question on a 5-point Likert scale. For the questions regarding optimal timing of end-of-life communication, they selected one answer from eight choices ranging from 'at the time of diagnosis of ILD' to 'do not discuss'. Full details of the questionnaire are available in the online supplement. The following data were also collected on the participant characteristics: age, gender, years of practice, type of hospital, number of patients with ILD treated in the last year, and experience with the national palliative care education programme[21].

Statistical analyses

The frequencies and percentages of eligible participants' responses to each item were calculated. A chi-square test were employed to compare the results of ideal vs. actual timing of end-of-life communication with patients with ILD. In the comparison of palliative care between patients with ILD and lung cancer, the 5-point Likert scale was regarded as continuous variables and t-tests were used to compare ILD and lung cancer. Effect size (ES) was calculated using Cohen's d. In questions regarding barriers to palliative care, the barriers were considered significant when the sum of the percentage for

'large barrier' and 'huge barrier' was more than 60%[18]. All statistical analyses were performed using commercially available software (JMP version 9.0: SAS Institute, Inc., Cary, NC, USA). A p-value <0.05 was considered statistically significant.

Results

Participant characteristics

Among the 3,423 eligible participants, 1,332 completed the questionnaire (response rate: 38.9%). The data of participants who were not engaged in the practice of ILD or had not cared for any patients with ILD in the last year were excluded from the final analysis (Figure 1). Thus, the participants were 1,023 pulmonary specialists and their characteristics are summarized in Table 1.

Palliative care practices for patients with ILD

Table 2 shows the current status of palliative care for patients with ILD. Dyspnea and cough were major symptoms, with 88.9% and 84.8% of the participants stating that patients with ILD often or always complained of dyspnea and cough, respectively. In particular, dyspnea was a symptom that was often or always problematic for more than 90% of participants. In terms of end-of-life communication, more than 60% of the participants reported that information given to patients or family members was occasionally or often changed, which indicated different levels of information were occasionally provided to patients and families. As shown in Figure S1, 25% of the participants had referred patients with ILD to a formal palliative care team, while the remaining 75% had never done so. Of the participants who had never referred patients with ILD to a formal palliative care team, 48% stated that a palliative care team was available, suggesting that it is still uncommon to consult a formal palliative care team for patients with ILD.

Ideal and actual timing of end-of-life communication with patients with ILD

There was a significant difference in the distribution of ideal and actual timing of end-of-life communication (Figure 2). Overall, the actual timing of end-of-life communication tended to be later

than physician-perceived ideal timing. The participants considered that the ideal timing of end-of-life communication with patients with ILD was at the 'initiation of home oxygen therapy' (27.8%). On the other hand, 34.4% of the participants reported the actual timing of end-of-life communication was at 'hospitalization due to worsening respiratory condition', which was relatively later.

Comparison of palliative care between patients with ILD and lung cancer

The pulmonary specialists experienced significantly greater difficulty in symptom relief (Figure 3A) and decision-making during end-of-life care (Figure 3B) for patients with ILD compared to those with lung cancer (ES 0.83; $p < 0.0001$, ES 0.70; $p < 0.0001$, respectively). Prescription of opioids for dyspnea on exertion (Figure 3C; ES 1.26; $p < 0.0001$) and dyspnea at rest (Figure 3D; ES 1.30; $p < 0.0001$) were significantly less frequent in patients with ILD than in those with lung cancer.

Barriers to optimal palliative care for patients with ILD

The questions concerning barriers and difficulties in palliative care for patients with ILD were classified into four domains: factors of diseases and treatments, factors of symptom relief, factors of psychosocial problems and factors of decision-making (Table 3). In factors of diseases and treatments, the difficulty of predicting the prognosis or disease progression (62.6%) , few established indicators to predict short-term prognosis (60.4%), and difficulty of predicting the onset of acute exacerbation (72.9%) were highlighted as significant physician-perceived barriers. Moreover, 61.7% of the participants rated the inadequate provision of home healthcare as a major barrier. In terms of factors of symptom relief, more than 70% said that having few established treatments for dyspnea was a significant barrier to palliative care. Other barriers were not having established treatments for cough (62.9%) or established indications and methods of sedation for symptom relief in the terminal phase of ILD (63.7%). Lack of social support for the patients and lack of psychological support for the family/survivors were psychosocial issues that posed important barriers. In addition, several barriers existed in the factors of decision-making: patients/families' lack of knowledge/understanding about the

disease (66.0%), difficulty understanding the prognosis (71.3%), difficulty accepting the disease's poor prognosis (64.5%) and difficulty understanding the limitations and complications of treatment (64.4%).

Discussion

To the best of our knowledge, this study is the largest nationwide survey of pulmonary specialists to explore current clinical practice and physician-perceived barriers related to palliative care for patients with ILD.

The present study revealed that pulmonary specialists perceived greater difficulty in providing palliative care, such as symptomatic relief and decision-making at the patient's end-of-life, for patients with ILD than for those with lung cancer. In palliative care for patients with advanced cancer, it is relatively common to employ a team approach that includes palliative care specialists, respiratory nurses, and psychologists[22]. On the other hand, the pulmonary specialists in this study were predominantly the ones to provide palliative care for patients with ILD, and referring them to a palliative care team was limited. To date, there is no international consensus on referral criteria of specialist palliative care for patients with ILD. Consistent with our results, former studies have demonstrated that patients with ILD received poorer access to palliative care than those with lung cancer[7,13]. Lindell et al. retrospectively reported that only 13.7% of 277 patients who died of IPF had been referred to a formal palliative care team and the majority (71%) were referred within 1 month of their death[23]. These findings suggest that multifaceted interventions, including a palliative care team approach and improved accessibility to palliative care, are urgently required for patients with ILD.

The survey showed that dyspnea and cough were two major and difficult to control symptoms in patients with ILD; however, pulmonary specialists prescribed opioids less frequently for patients with ILD than for those with lung cancer. Most patients with ILD experience breathlessness at the end-of-life[7,13]. Glaspole et al. demonstrated that severity of cough and dyspnea as well as depression and decline of FVC were associated with health-related QOL in patients with IPF[8]. These findings indicate that appropriate management for dyspnea and cough are critical for symptomatic relief for patients with ILD; however, few established treatments and guidelines for dyspnea and cough of ILD are available,

and these were identified as significant barriers in palliative care for patients with ILD. In patients with advanced cancer, international guidelines recommend the use of systemic opioids for dyspnea that is not adequately relieved by non-pharmacologic therapies[24,25]. Meanwhile, only a few clinical trials have demonstrated the safety and efficacy of systemic opioid in relieving severe dyspnea in patients with ILD[26-28]. Well-designed prospective clinical studies are urgently needed to establish pharmacotherapy, including systemic opioids, for symptomatic relief of dyspnea and cough in patients with ILD.

Optimal timing of end-of-life communication in patients with ILD remains controversial in clinical settings[9,29]. This survey showed that the 'initiation of home oxygen therapy' was the point in time most frequently identified by physicians as ideal for end-of-life communication with patients with ILD. A previous study mentioned that patients with IPF experienced deterioration of QOL together with severe dyspnea and fatigue already two years before death[30], suggesting the importance of early intervention in palliative care in IPF. A Swedish nationwide cohort study revealed that the median survival time from the initiation of oxygen therapy in patients with ILD was only 8.4 months[7], indicating that end-of life communication should definitely be performed at the initiation of home oxygen therapy. On the other hand, the most frequent actual timing reported in this survey was at 'hospitalization due to worsening respiratory condition', which was later than the physician-perceived ideal timing. Predicting the prognosis and disease progression of patients with ILD is often difficult for attending physicians because of the heterogeneity of the disease behavior and clinical course in ILD, and this was one of the barriers to palliative care for patients with ILD identified in this survey. In fact, death from ILD was more likely to be unexpected than death from lung cancer[7]. Taken together, early intervention with end-of life communication based on disease behavior is needed in palliative care for patients with ILD.

The results of this research reinforce the importance of closer communication among clinicians, patients, and their families in the decision-making for patients with ILD. Lack of knowledge about the diseases in patients and their families, as well as difficulty understanding the limitations of treatment and the prognosis, were significant barriers in palliative care for patients with ILD. Previous studies showed that patients with ILD and their families tended to have insufficient knowledge in end-of-life discussions and a poor understanding of their prognosis and medical condition at the end stage[13,31,32]. Because

clinical course in ILD are heterogeneous, the prediction of disease progression and prognosis of patients with ILD are uncertain and not easy for clinicians. Even so, both patients with ILD and their family members want to receive more information from clinicians[31]. More frequent and detailed discussions among attending physicians, patients, and their families are essential to integrate decision-making in a more timely and appropriate way. Additionally, further studies are warranted to develop a clinical model that can predict disease progression and prognosis and identify the appropriate timing for end-of-life discussions and decision-making for patients with ILD.

In the present study, only one-fourth of the participant (pulmonary specialists) had experience to refer patients with ILD to a formal palliative care team, even though they perceived difficulty in providing palliative care. The importance of palliative care for patients with non-malignant lung disease has been recognized in clinical practice in Japan, however, a collaborative care approach of pulmonary specialists and palliative specialists has not been fully implemented in the practice of ILD. In Japan, health insurance covers referring to a formal palliative care team for patients with advanced cancer, but does not for those with ILD yet. This may be one reason why pulmonary specialists hesitate to refer patients with ILD to a formal palliative care team. Additionally, ILD has a lower incidence than lung cancer, thus, even pulmonary specialists may not have many opportunities to experience end-of-life care of ILD patients. Indeed, although all the 1,023 participants were engaged in the practice of ILD, 19.1% had no ILD patients died within the last year. Recently, the JRS and the Japan Society for Respiratory Care and Rehabilitation jointly published a statement on non-malignant respiratory diseases palliative care (published by Japanese in 2021). In the clinical practice, collaborative care with pulmonary specialists and palliative specialists, as well as dissemination of the statement and insurance coverage of palliative care team approach for ILD, are needed to improve palliative care in patients with ILD.

The strengths of this study include that a random sampling from a large number of certified pulmonary specialists obtained representative responses, and lung cancer was used as a comparative reference to make the interpretation of results reasonable. Nonetheless, this study has several limitations. First, patients and family members were not surveyed. In the future, research that directly engages patients and their families may yield important insights into palliative care for ILD. Second, although

this survey was nationwide and the number of participants (pulmonary specialists) was large, the response rate was modest. Third, all the 1,023 participants were engaged in the practice of ILD, but not all of them cared for many patients with ILD in the daily clinical practice. In this survey, 29.4% of the participants cared for 1 to 10 patients with ILD in the last year. As ILDs are not common diseases, even pulmonary specialists, who are the main physicians caring for patients with ILD in Japan, care for a limited number of patients with ILD.

In conclusion, pulmonary specialists experienced greater difficulty in providing palliative care for patients with ILD than for those with lung cancer; however, the palliative team care approach is still less common in patients with ILD. Various ILD-specific barriers and difficulties exist in palliative care for patients with ILD. Therefore, further studies are urgently needed to develop multifaceted interventions including a palliative care team approach, to establish pharmacotherapy for dyspnea and cough and to build a clinical model that can predict disease progression and prognosis, thereby improving palliative care for patients with ILD.

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Declaration of conflicts of interest

R. Tachikawa reports personal fees from Boehringer Ingelheim, outside the submitted work. K. Tomii reports personal fees from Boeringer-Ingelheim and Shionogi, outside the submitted work.

Y. Kondoh reports personal fees from Asahi Kasei Pharma Corp, Boehringer Ingelheim, Chugai Pharmaceutical Co., Ltd., Healios K.K., Janssen Pharmaceutical KK, Shionogi Co, Ltd., Taiho Pharmaceutical Co., Ltd., Bristol Myers Squibb, Eisai Co, Ltd, KYORIN Pharmaceutical Co, Ltd, Mitsubishi Tanabe Pharma, NIPPON SHINYAKU CO., LTD, Novartis Pharma KK, and Teijin Pharma

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T. Fujisawa, N. Akiyama, T. Morita, T. Koyauchi, Y. Matsuda, M. Mori, M. Miyashita, H. Tomioka, S. Hagimoto, and T. Suda declare that there is no conflict of interest.

Ethics approval declaration

This study was a cross-sectional survey of pulmonary physicians and approval from the ethics committee was waived.

Authorship

T.F., N.A., T.M.: Conception and design of the work, acquisition, analysis and interpretation of data, statistical analysis and manuscript writing; T.K., Y.M., M.M., M.M.: conception and design of the work, acquisition, analysis and interpretation of data; R.T., K.T., H.T., S.H., Y.K., Y.I.: conception and design of the work, acquisition; T.S.: conception and design of the work, acquisition, analysis and interpretation of data and administrative support.
All authors reviewed and confirmed the manuscript.

Abbreviations:

ES, effect size; ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis; JRS, Japanese Respiratory Society; QOL, quality of life

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Table 1. Participant characteristics

	All participants (n = 1023)
Sex	
Male	824 (80.5)
Female	197 (19.3)
No response	2
Age (mean, SD)	48.8 ± 10.9
Years of practice (median, range)	23.2 (2–57)
Type of hospital	
University hospital	255 (24.9)
General hospital >500 beds	183 (17.9)
General hospital <500 beds	459 (44.9)
Medical clinic	121 (11.8)
Other	5 (0.5)
Experience with the national palliative care education programme	832 (81.3)
Number of ILD patients cared for in the last year	
1-10	301 (29.4)
11–20	299 (29.2)
21–30	189 (18.5)
>31	226 (22.1)
No response	8 (0.8)
Number of ILD patients who died within the last year	
0	196 (19.1)
1–2	265 (25.9)
3–4	287 (28.1)
5-9	206 (20.1)
>10	61 (6.0)
No response	8 (0.8)

Note. SD: standard deviation; ILD: interstitial lung disease

Table 2. Current practices of palliative care for patients with ILD

Frequency of symptoms (patient complaints)	Never	Rarely	Occasionally	Often	Always
Dyspnea (n = 1019)	0.0	0.1	11.1	65.8	23.1
Cough (n = 1020)	0.0	0.5	14.7	70.0	14.8
Pain (n = 1014)	9.7	66.5	22.1	1.5	0.3
Fatigue (n = 1015)	1.1	17.5	52.5	26.1	2.8
Appetite loss (n = 1020)	0.6	7.5	42.3	45.3	4.4
Anxiety (n = 1019)	0.1	8.9	47.6	37.5	5.9
Depression (n = 1016)	0.4	21.0	53.1	23.1	2.4
Insomnia (n = 1017)	0.5	21.3	54.7	22.1	1.4
Frequency of symptoms (physicians consider problematic)					
Dyspnea (n = 1020)	0.1	1.0	7.1	40.6	51.3
Cough (n = 1019)	0.2	3.3	23.5	47.5	25.5
Pain (n = 1017)	15.6	41.2	26.8	12.4	3.9
Fatigue (n = 1016)	2.0	22.8	47.9	22.2	5.0
Appetite loss (n = 1017)	0.6	11.5	39.5	37.2	11.2
Anxiety (n = 1017)	0.5	12.9	42.0	36.5	8.2
Depression (n = 1018)	1.0	16.2	42.2	33.5	7.1
Insomnia (n = 1019)	1.5	22.3	48.1	23.7	4.4
Frequency of end-of-life communication					
How often do you discuss end-of-life care with patients? (n = 1013)	0.6	12.3	40.4	34.3	12.4
Have you ever discussed end-of-life care with family members alone, excluding the patient? (n = 1014)	4.9	22.0	42.6	24.8	5.7
How often was information given to patients or family members changed? (n = 1015)	5.5	26.8	43.8	20.7	3.2
How often did health care professionals decide on end-of-life care without including the patients or family members? (n = 1014)	49.3	40.5	8.3	1.8	0.1
What do you specifically discuss with patients?					
Past clinical course and current medical condition (n = 1014)	0.0	0.9	11.5	34.4	53.2
Estimated prognosis (n = 1014)	0.4	8.8	34.8	37.2	18.8
Endotracheal intubation/ventilator management (n = 1013)	1.3	9.7	27.3	28.3	33.4
DNAR (n = 1011)	1.7	10.2	26.2	30.8	31.2
Place to spend the final days (e.g., at home) (n = 1013)	1.5	9.9	26.6	35.0	27.0

Note. ILD: interstitial lung disease; DNAR: do not attempt resuscitation
Data are expressed as percentages.

Table 3. Barriers to palliative care of patients with ILD

Factors for diseases and treatments	Not	Minimal	Moderate	Large	Huge
Difficult to predict the prognosis or disease progression[a] (n = 1012)	0.6	8.5	28.3	**40.5**	**22.1**
Few established indicators to predict short-term prognosis[a] (n = 1010)	1.0	9.2	29.4	**39.2**	**21.2**
Difficult to predict the onset of acute exacerbation[a] (n = 1013)	1.0	6.3	19.8	**40.7**	**32.2**
Few established indicators to predict, no improvement expected (n = 1014)	1.2	11.5	28.8	37.4	21.1
Limited time for each patient (n = 1013)	1.8	14.2	32.2	30.7	21.1
Few professional nurses with knowledge of palliative care for ILD (n = 1014)	1.9	14.1	29.9	35.1	19.0
Insufficient system to provide multidisciplinary palliative care (n = 1013)	1.3	13.7	30.8	35.5	18.7
Inadequate provision of home healthcare[a] (n = 1014)	1.7	9.1	27.6	**38.7**	**23.0**
Factors for symptom relief					
Few established treatments for cough[a] (n = 1013)	1.2	7.7	28.2	**38.6**	**24.3**
Few established treatments for dyspnea[a] (n = 1013)	1.0	6.9	20.9	**39.5**	**31.7**
Few established treatments for physical symptoms other than respiratory symptoms (e.g., anorexia, fatigue) (n = 1012)	1.0	7.9	33.3	39.3	18.5
Few established methods for relieving mental symptoms (anxiety, depression, insomnia, etc.) (n = 1013)	0.9	8.4	37.2	37.3	16.2
Lack of established methods for alleviating spiritual (existential) pain (n = 1013)	1.0	10.2	34.7	36.7	17.4
Palliative care for patients awaiting lung transplantation has not been established (n = 1013)	4.6	15.6	31.6	32.0	16.3
The effectiveness of palliative care in the early stage after diagnosis of ILD has not been established (n = 1009)	2.5	14.2	31.8	35.0	16.6
Not knowing when to refer patients to the palliative care team (n = 1009)	6.0	23.5	35.1	25.6	9.8
The effectiveness of palliative care in parallel with treatment for acute exacerbations has not been established (n = 1011)	2.8	14.9	33.1	33.2	16.1
Lack of established palliative care for patients who do not show improvement despite appropriate treatment (n = 1013)	2.5	12.5	29.6	37.0	18.4
The indications and methods of sedation for symptom relief in the terminal phase of ILD have not been established[a] (n = 1014)	2.1	10.5	23.8	**38.0**	**25.7**

Factors of psychosocial problems	Not	Minimal	Moderate	Large	Huge
The patient has financial problems (n = 1012)	0.8	9.3	32.2	37.9	19.8
Lack of social support for the patient (e.g., living alone)[a] (n = 1013)	0.5	3.5	19.1	**45.1**	**31.9**
Lack of psychological support for the family/survivors[a] (n = 1013)	0.6	6.1	31.5	**42.9**	**18.9**
Disagreement between patient and family regarding treatment goals (n = 1012)	0.9	9.9	31.2	36.8	21.2
Lack of psychological support professionals (n = 1012)	0.5	8.9	32.3	40.7	17.6
Factors of decision-making					
Lack of knowledge/understanding of patient/family for the disease [a] (n = 1012)	0.6	7.9	25.5	**40.5**	**25.5**
Difficult for patients/families to understand the prognosis[a] (n = 1013)	0.4	6.1	22.2	**41.1**	**30.2**
Difficult for patients/families to accept the disease with poor prognosis [a] (n = 1011)	0.7	8.0	26.8	**37.2**	**27.3**
Difficulty for patient/family to understand the limitations and complications of treatments for ILD[a] (n = 1011)	0.9	7.6	27.0	**41.3**	**23.1**
Not knowing when it is appropriate to discuss end-of-life issues with the patient in advance (n = 1011)	2.6	13.6	34.8	33.8	15.2
Not knowing how to deal with patients with dementia or other conditions that make treatment decisions difficult (n = 1011)	2.7	17.6	35.5	30.5	13.7
Difficulty in supporting the decision-making process for patients awaiting lung transplantation (n = 1003)	5.2	15.7	36.0	30.0	13.2

Note. ILD: interstitial lung disease

Data are expressed as percentages.

[a] Barriers considered significant. Large + Huge >60%

Figure legends

Figure 1. Schematic of the study flow chart

ILD: interstitial lung disease

Figure 2. Ideal and actual timing of end-of-life communication with patients with ILD

The proportion of the results of ideal vs. actual timing of end-of-life communication was significantly different ($p < 0.0001$, Chi-square test). Ideal timing (n = 1017), actual timing (n = 1016).

ILD: interstitial lung disease

Figure 3. Comparison of palliative care between patients with ILD and lung cancer

a. Do you experience any difficulties in relieving symptoms?
   ILD 3.79 (SD 0.92) vs LC 3.01 (SD 0.97); ES 0.83; $p < 0.0001$
b. Do you experience any difficulties with decision-making at the patient's end-of-life?
   ILD 3.55 (SD 0.93) vs LC 2.90 (SD 0.93); ES 0.70; $p < 0.0001$
c. Do you prescribe opioids (e.g., morphine) for dyspnea on exertion?
   ILD 2.48 (SD 1.03) vs LC 3.85 (SD 1.15); ES 1.26; $p < 0.0001$
d. Do you prescribe opioids (e.g., morphine) for dyspnea at rest?
   ILD 2.62 (SD 1.07) vs LC 4.00 (SD 1.06); ES 1.30; $p < 0.0001$
e. Do you inform the patient that the disease cannot be cured?
   ILD 4.37 (SD 0.81) vs LC 4.59 (SD 0.71); ES 0.29; $p < 0.0001$
f. Do you talk to the patient about endotracheal intubation/ventilator?
   ILD 3.75 (SD 1.07) vs LC 3.99 (SD 1.11); ES 0.22; $p < 0.0001$

Bars show the mean with 95% confidence intervals.

ES: effect size; ILD: interstitial lung disease; LC: lung cancer; SD: standard deviation
*$p < 0.0001$

Figure 1

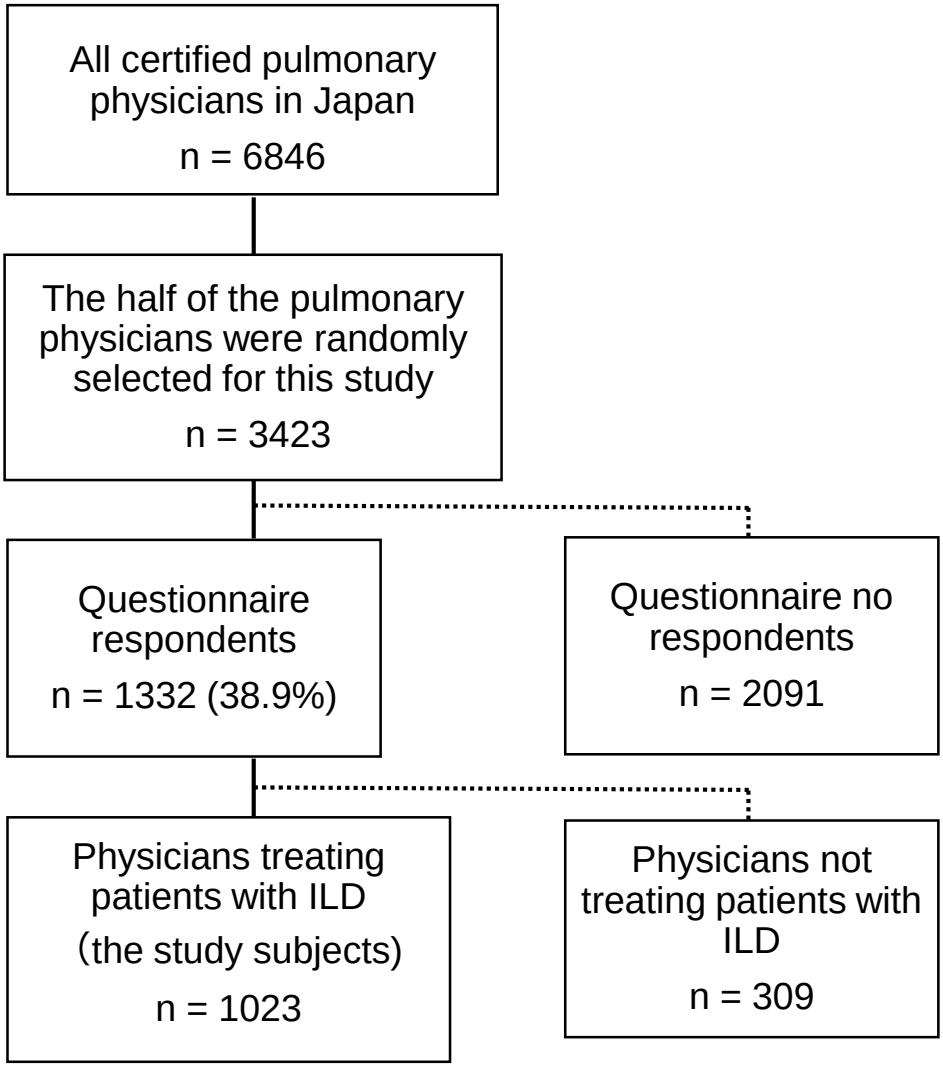

All certified pulmonary physicians in Japan
n = 6846
The half of the pulmonary physicians were randomly selected for this study
n = 3423
Questionnaire respondents
n = 1332 (38.9%)
Questionnaire no respondents
n = 2091
Physicians treating patients with ILD
(the study subjects)
n = 1023
Physicians not treating patients with ILD
n = 309

Figure 2

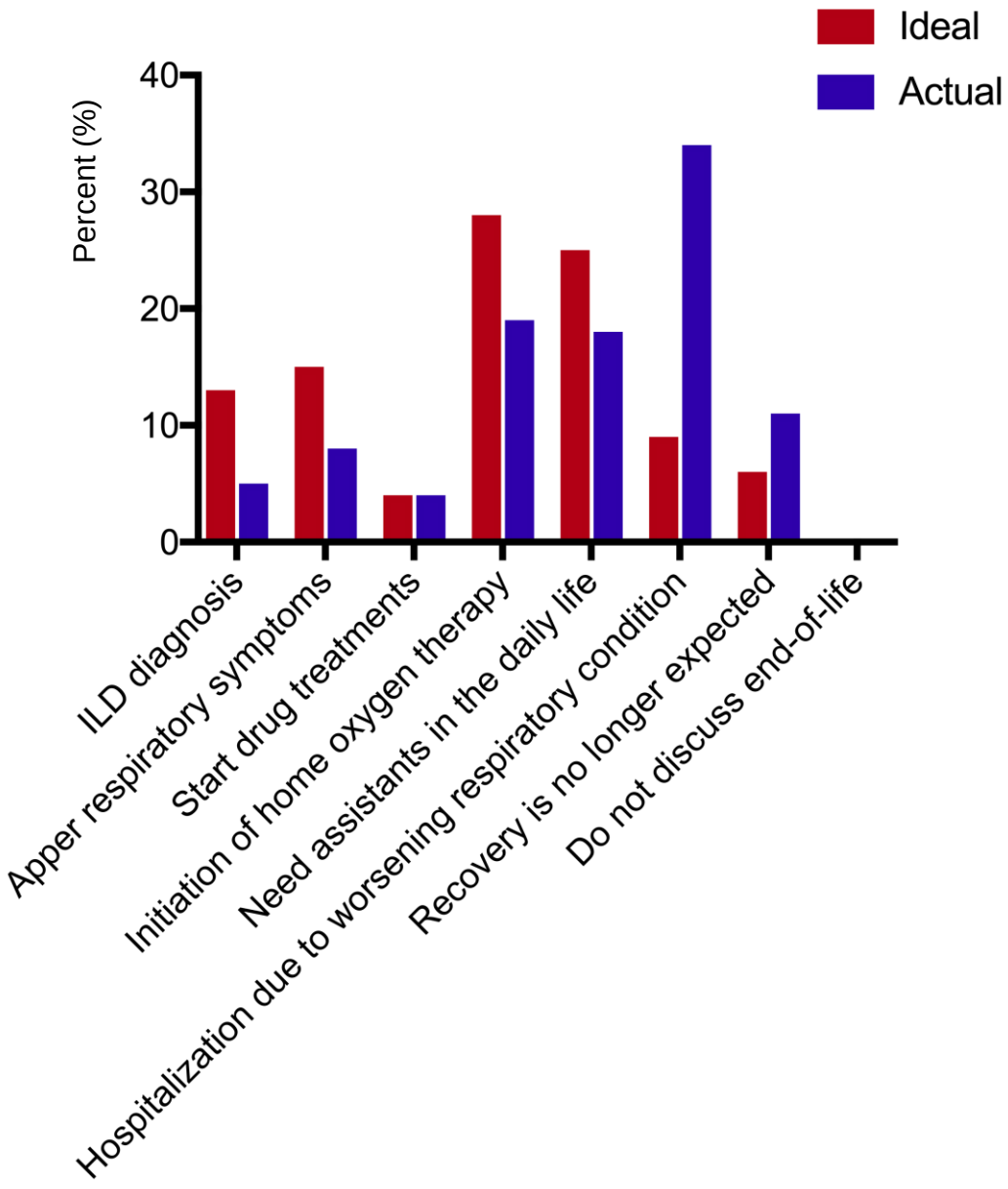
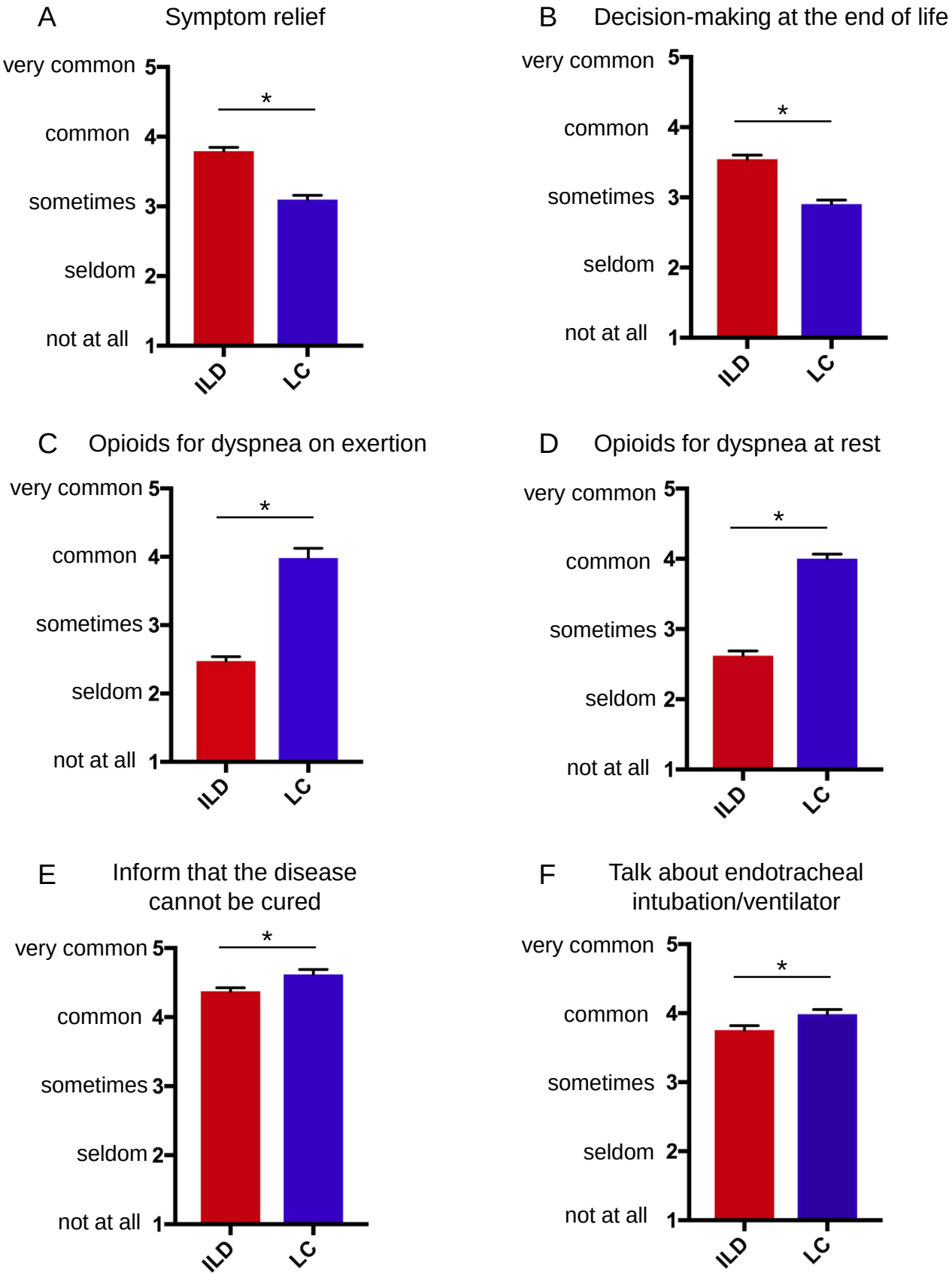

Ideal
Actual
Percent (%)
40
30
20
10
0
ILD diagnosis
Apper respiratory symptoms
Start drug treatments
Initiation of home oxygen therapy
Need assistants in the daily life
Hospitalization due to worsening respiratory condition
Recovery is no longer expected
Do not discuss end-of-life

Figure 3


A
Symptom relief
very common 5
common 4
sometimes 3
seldom 2
not at all 1
*
ILD
LC
B
Decision-making at the end of life
very common 5
common 4
sometimes 3
seldom 2
not at all 1
*
ILD
LC
C
Opioids for dyspnea on exertion
very common 5
common 4
sometimes 3
seldom 2
not at all 1
*
ILD
LC
D
Opioids for dyspnea at rest
very common 5
common 4
sometimes 3
seldom 2
not at all 1
*
ILD
LC
E
Inform that the disease cannot be cured
very common 5
common 4
sometimes 3
seldom 2
not at all 1
*
ILD
LC
F
Talk about endotracheal intubation/ventilator
very common 5
common 4
sometimes 3
seldom 2
not at all 1
*
ILD
LC