Original research

Quality of dying and death in patients with interstitial lung disease compared with lung cancer: an observational study

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ABSTRACT

Background There is limited knowledge regarding the quality of dying and death (QODD) and end-of-life interventions in patients with interstitial lung disease (ILD). Hence, differences in QODD and end-of-life interventions between patients with ILD and those with lung cancer (LC) remain poorly understood.

Methods The primary aim of this study was to explore the differences in QODD and end-of-life interventions among patients dying with ILD versus those dying with LC. We performed a mail survey to quantify the QODD of a bereaved family's perspective using the Good Death Inventory (GDI) score. Moreover, we examined the end-of-life interventions by medical chart review.

Results Of 361 consecutive patients analysed for end-of-life interventions, 167 patients whose bereaved families completed questionnaires were analysed for QODD. Patients with ILD had lower GDI scores for QODD than those with LC (p=0.04), particularly in domains related to 'physical and psychological distress relief' and 'prognosis awareness and participation in decision making' (p=0.02, respectively). In end-of-life interventions, patients with ILD were less likely to receive specialised palliative care services (8.5% vs 54.3%; p<0.001) and opioids (58.2% vs 73.4%; p=0.003). Additionally, lower frequencies of participation of patients with ILD in end-of-life discussion were also observed (40.8% vs 62.4%; p=0.007).

Conclusion Patients with ILD had lower QODD and poorer access to palliative care and decision making than those with LC. Additional efforts to improve QODD in patients with ILD, particularly in symptom relief and decision-making processes, are urgently warranted.

Key messages

What is the key question?

► Are there differences in quality of dying and death (QODD) and end-of-life interventions between patients with interstitial lung disease (ILD) and those with lung cancer?

What is the bottom line?

► Patients with ILD had lower QODD and poorer access to palliative care and decision making than those with lung cancer.

Why read on?

► The present study highlights the necessary improvement to achieve a good death in patients with ILD.

INTRODUCTION

Interstitial lung diseases (ILDs) are progressive and incurable diseases that induce fibrotic destruction of the lung parenchyma.[1 2] Among ILDs, idiopathic pulmonary fibrosis (IPF) is the most common form of fibrosing ILDs and has a worse prognosis than most malignancies, with a median survival of approximately 3 years from the time of diagnosis.[2] ILDs are characterised by cough, fatigue, anxiety, depression and deteriorating breathlessness. Notably, patients with ILD often experience equivalent or more severe symptoms for longer periods versus those with cancer.[3 4]

Palliative care for non-malignant diseases, including ILD, has been attracting attention. However, palliative care remains underused in patients with ILD.[5] Our group recently conducted a questionnaire survey for pulmonologists and reported that these specialists experience greater difficulty in providing palliative care for patients with IPF than for those with lung cancer (LC).[6] Several unmet needs in palliative care for ILD have been proposed,[7] but the quality of dying and death (QODD) and end-of-life interventions in clinical practice in patients with ILD have not been fully assessed yet, and the issues that need immediate improvement remain poorly understood.

This study was conducted to explore the differences in QODD and end-of-life interventions between patients with ILD and those with LC. The reason for the comparison with patients dying of LC was that an integrated model of palliative care is available for patients with cancer,[8] and we expected that the comparison could provide a clinically interpretable insight.

METHODS

We conducted the bereaved survey by sending self-reported questionnaires to the family members of

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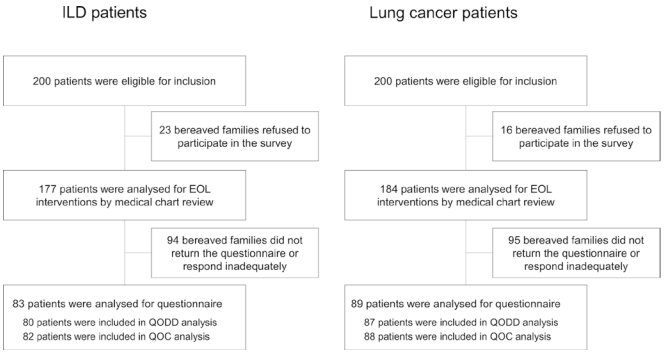

Figure 1 Diagram of patient flow in the study. EOL, end of life; ILD, interstitial lung disease; QOC, quality of care; QODD, quality of dying and death.

decedents with ILD and those with LC in Japan. Additionally, we performed a medical chart review of consecutive decedents with ILD and those with LC. The bereaved survey measurements were linked to the same patient's information obtained by medical chart review. Informed consent was based on the choice to opt out. We sent written explanations regarding this study to the bereaved family members via mail, and those who refused to participate were excluded from this study.

Setting

This multicentre study was conducted at four major acute general hospitals in the western part of Shizuoka Prefecture, Japan. Participating hospitals were regarded representative of the region, considering that they are four of the six general hospitals with ≥500 beds and a respiratory department in this geographical area: Hamamatsu University Hospital (613 beds), Seirei Mikatahara Hospital (934 beds), Seirei Hamamatsu Hospital (750 beds) and Iwata City Hospital (500 beds).

In Japan, palliative care focuses mainly on patients with cancer, and specialised inpatient units and hospital consultation services for inpatients and outpatients are available. All four participating hospitals have hospital consultation services, and Seirei Mikatahara Hospital has a 27-bed inpatient hospice (palliative care unit), which is usually provided to patients with cancer because it is covered under medical insurance for such patients. Moreover, home physicians provide specialised home services throughout the region for patients with and without cancer.

Subjects and procedures

The medical records of consecutive patients who died in the participating institutes from October 2015 to March 2019 were reviewed. We consecutively enrolled 400 pairs (200 with ILD and 200 with LC) of patients and family members (one family member per patient). The sample size was determined by the number of patients in the area during the study period. Inclusion criteria were as follows: (1) diagnosis of fibrosing ILD or LC (for patients diagnosed with both ILD and LC, the disease that resulted in death was determined by reviewing the medical records prior to conducting statistical analyses); (2) age >20 years; and (3) patients with family members aged >20 years. Exclusion criteria were as follows: (1) family members who lacked the capacity to complete the questionnaire (as a result of dementia, cognitive failure, psychiatric illness, language difficulty or vision loss) and (2) family members who had severe emotional distress determined by their primarily responsible physician. We sent questionnaires to bereaved family members via mail between October and November 2019 and requested them to complete and return the questionnaires to the study office within 1 month.

Outcomes

The outcome of most interest was QODD, as rated on the Good Death Inventory (GDI) (online supplemental table E1).[9–11] The other outcomes of interest were symptom severity at the end of life, as rated on the Memorial Symptom Assessment Scale[12 13]; family-perceived quality of care (QOC), as rated on the Care Evaluation Scale (CES)[14]; end-of-life interventions, as per the medical records, and details of end-of-life discussion[15]; and the association between QODD and interventions (ie, palliative care access and the patient's participation in end-of-life discussion). The details of each measurement are described in the online supplemental file.

Statistical analysis

First, we compared the characteristics of the patients and their bereaved family between the two diagnostic groups. We used Fisher's exact test for categorical variables and Student's t-test or Mann-Whitney U test for quantitative variables as appropriate. Summary statistics were calculated as numbers (with percentages), median (with IQR) and mean (with SD) as appropriate.

Second, we tested the association of patient diagnosis with all the outcomes (symptom burden, QODD, QOC and end-of-life interventions) using Fisher's exact test, Student's t-test or Mann-Whitney U test as appropriate. P values adjusted for confounders of the association between patient diagnosis and outcomes were also calculated according to regression models: logistic regression models for categorical outcome variables and linear regression models for quantitative outcome variables. QODD and QOC were adjusted for patient's age at death, patient's sex, age of the family member, and relationship between the patient and the family, whereas the other outcomes were adjusted for patient's age at death and patient's sex. Because the incidence of missing values was very low for independent variables (for only one participant, information regarding the bereaved family member's characteristics was missing), imputation was not performed. In comparing QODD and QOC between groups, we calculated the effect size (ES; Hedges' g) to evaluate the degree of these differences. For interpretation, Hedges' g values of 0.2, 0.5 and 0.8 were regarded as small, moderate and large differences, respectively.

Finally, we hypothesised that the implementation of specialised palliative care and patients' participation in end-of-life discussions—which, according to a Swedish national population-based study, is lacking for patients with ILD[4]—may be associated with QODD in patients dying of ILD. This hypothesis is based on the empirical finding that these interventions were associated with a higher QODD in patients with cancer.[16–19] We divided patients with ILD into three groups based on the presence or absence of palliative care access (ie, specialised palliative care services, opioid use or both) and their participation in end-of-life discussions: patients without both palliative care access and participation in end-of-life discussion (group A); patients with either palliative care access or participation in end-of-life discussion (group B); and patients with both palliative care access and participation in end-of-life discussion (group C). Each group was ranked according to the intensity of the interventions, and the Jonckheere-Terpstra trend test was performed to explore the associations between these interventions and GDI score. Each

Table 1 Patients and bereaved family characteristics

	ILD			Lung cancer		
	Total (n)	n (%)		Total (n)	n (%)	P value
Patients	177			184		
Age, years		76.0 (8.3)			74.9 (9.7)	0.24
Sex						0.40
Male		137 (77.4)			135 (73.4)	
Female		40 (22.6)			49 (26.6)	
Institution						<0.001
Seirei Mikatahara Hospital		75 (42.4)			115 (62.5)	
Seirei Hamamatsu Hospital		37 (20.9)			19 (10.3)	
Hamamatsu University Hospital		33 (18.6)			18 (9.8)	
Iwata City Hospital		32 (18.1)			32 (17.4)	
LTOT, yes		92 (52.0)			29 (15.8)	<0.001
Type of disease						
IPF		78 (44.1)	Adenocarcinoma		93 (50.8)	
Non-IPF IIP		58 (32.8)	Squamous cell carcinoma		35 (19.1)	
CTD-IP		36 (20.3)	Small cell carcinoma		25 (13.7)	
CHP		3 (1.7)	Clinical diagnosis		16 (8.7)	
Others		2 (1.1)	Others		14 (7.7)	
Cause of death						
Acute exacerbation		99 (55.9)	Cancer progression		180 (97.8)	
Exacerbation of chronic respiratory failure		49 (27.7)	Treatment-related death		2 (1.1)	
Respiratory infection		15 (8.5)	Infection		1 (0.5)	
Others		14 (7.9)	Others		1 (0.5)	
Months from diagnosis to death		31 (6–61)			11 (4–28)	<0.001
Bereaved family members	83			88		
Age, years						0.53
>49		11 (13.3)			10 (11.4)	
50–59		15 (18.1)			14 (15.9)	
60–69		25 (30.1)			36 (40.9)	
≥70		32 (38.6)			28 (31.8)	
Sex						0.25
Male		23 (27.7)			32 (36.4)	
Female		60 (72.3)			56 (63.6)	
Relationship to patient						0.17
Husband/wife		51 (61.4)			51 (58.0)	
Child of patient		29 (34.9)			27 (30.7)	
Others		3 (3.6)			10 (11.4)	
Frequency of visits during the last hospitalisation						0.40
Every day		59 (71.1)			59 (67.0)	
4–6 days per week		8 (9.6)			16 (18.2)	
1–3 days per week		13 (15.7)			11 (12.5)	
No visit		3 (3.6)			2 (2.3)	

Categorical variables are expressed as number (percentage).
Quantitative variables are expressed as mean (SD) or median (IQR).
Fisher's exact test was used to analyse categorical variables, and Student's t-test or Mann-Whitney U test was used to analyse quantitative variables as appropriate.
CHP, chronic hypersensitivity pneumonitis; CTD-IP, connective tissue disease-related interstitial pneumonia; ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis; LTOT, long-term oxygen therapy; non-IPF IIP, idiopathic interstitial pneumonia excluding idiopathic pulmonary fibrosis.

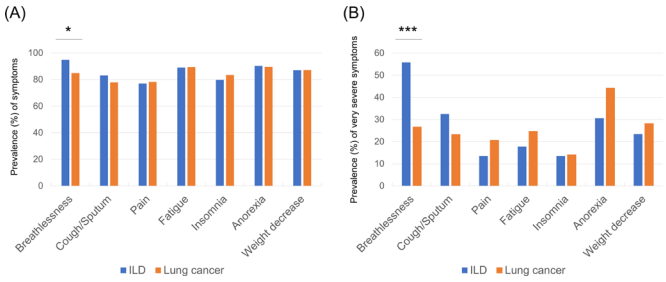

Figure 2 (A) Prevalence (%) of symptoms in ILD compared with lung cancer at end of life. (B) Prevalence (%) of very severe symptoms in ILD compared with lung cancer at end of life. *P<0.05, **P<0.01, ***P<0.001 (Fisher's exact test). ILD, interstitial lung disease.

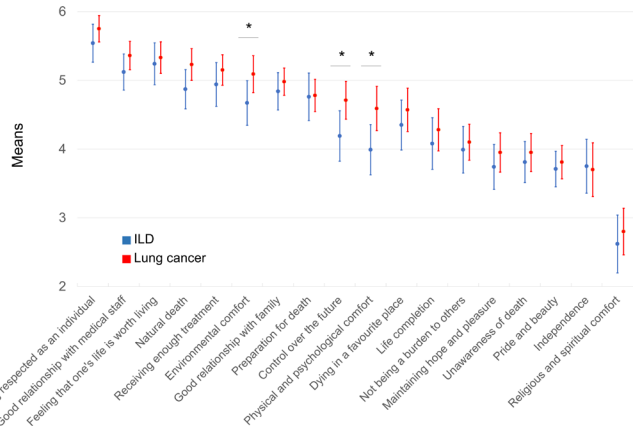

Figure 3 Domain scores of quality of dying and death according to groups. Plots and error bars indicate mean and 95% CI. Scores in the quality of dying and death domains were measured using the Good Death Inventory. Scores range from 1 to 7 (higher scores indicate higher perceived quality of dying and death). *P<0.05 (Student's t-test). ILD, interstitial lung disease.

group was ranked as follows: group A=1; group B=2; and group C=3.

A two-sided test was used to determine significant differences, and the significance level was set at p<0.05. Adjustment for multiple testing was not conducted due to the exploratory nature of this study. All statistical analyses were performed using EZR V.1.51 (Saitama Medical Center, Jichi Medical University, Saitama, Japan) software.[20]

RESULTS

Among the 400 eligible pairs of patients and families, 39 families refused to participate in this study and 361 were included in the medical chart review survey: 177 with ILD and 184 with LC. Of these, 172 participants who responded adequately to the questionnaire were included in the bereaved questionnaire survey: 83 with ILD and 89 with LC. Because of missing data for the variable of interest, five participants were excluded from the QODD analysis and two were excluded from the QOC analysis (figure 1). The median time interval from patient death to survey participation was 19 months (IQR: 14–27 months).

Characteristics of patients and families

The baseline characteristics of patients at the time of last hospitalisation and the bereaved family members are shown in table 1. There were no differences found between the two groups in terms of age and sex. The frequency of long-term oxygen therapy usage was higher in patients with ILD versus those with LC (52.0% vs 15.5%; p<0.001). IPF was the most common type of ILD (44.1%), followed by idiopathic interstitial pneumonia excluding IPF (32.8%) and ILD associated with collagen tissue diseases (20.3%). More than half of the patients with ILD died due to acute exacerbations, and the median survival time from the time of diagnosis was 31 months (IQR: 6–61 months). Approximately half of the patients with LC had adenocarcinoma (50.8%), followed by squamous cell carcinoma (19.1%) and small cell carcinoma (13.7%). Most patients with LC (97.8%) died due to cancer progression, with a median survival of 11 months from the time of diagnosis. The characteristics of bereaved family members who responded to the questionnaires were similar between the two groups in terms of age, sex, relationship to patients and frequency of visits. There was no significant difference in the characteristics between patients who responded to the questionnaire and those who did not (ILD: online supplemental table E2; LC: online supplemental table E3).

Symptom burden at end of life

Symptom prevalence reported by bereaved families in both groups is shown in figure 2. Patients with ILD were more likely to experience breathlessness at the end of life than those with LC (94.8% vs 84.9%; p=0.043). Of note, the prevalence of the other six symptoms was similar between the two groups (figure 2A). Furthermore, patients with ILD had a significantly higher prevalence of very severe breathlessness than those with LC (55.8% vs 26.7%; p<0.001) (figure 2B).

Quality of dying and death

Patients with ILD had a significantly lower mean GDI score for QODD than those with LC (4.33 vs 4.57; ES=−0.31; p=0.04) (online supplemental table E4). Domain scores according to groups are provided in figure 3. Among the domains, 'physical and psychological comfort (domain related to physical and psychological distress relief)' (3.99 vs 4.59; ES=−0.38; p=0.02), 'environmental comfort (domain related to circumstances of the final place)' (4.67 vs 5.09; ES=−0.31; p=0.048) and 'control over the future (domain related to prognosis awareness and participation in decision making)' (4.19 vs 4.71; ES=−0.35; p=0.02) were significantly lower in patients with ILD versus those with LC. These associations remained significant after adjustment for confounders.

Quality of care

The results for the QOC are presented in online supplemental table E5. Consistent with the findings for QODD, patients with ILD had a significantly lower mean CES score for QOC than those with LC (4.46 vs 4.72; ES=−0.37; p=0.02). Similar to the results obtained for QODD, the domains of 'physical care by physician', 'psycho-existential care', 'physician's explanation to the patient' and 'environment' were significantly lower in patients with ILD versus those with LC (p<0.05 for all).

Interventions at end of life

The details of end-of-life interventions are summarised in table 2. Of those with ILD, 168 patients died in the general ward (94.9%), 8 died in the intensive care unit (4.5%), and only 1 patient died in an inpatient hospice (0.6%). In contrast, among those with LC, 67 patients (36.4%) died in an inpatient hospice

Table 2 Interventions at end of life

	ILD, n=177	Lung cancer, n=184	P value	Adjusted p value*
Place of death			<0.001	<0.001†
General ward	168 (94.9)	117 (63.6)		
ICU	8 (4.5)	0 (0.0)		
Hospice	1 (0.6)	67 (36.4)		
Opioid use at the last hospitalisation	17 (9.6)	59 (32.1)	<0.001	<0.001
Benzodiazepine use at the last hospitalisation	22 (12.4)	29 (15.8)	0.37	0.51
Referral to specialised palliative care services	15 (8.5)	100 (54.3)	<0.001	<0.001
Number of diagnostic tests during the last 7 days of life				
Radiographs	3 (2–5)	1 (0–2)	<0.001	<0.001
Blood tests	3 (2–4)	1 (0–2)	<0.001	<0.001
Medical intervention during the last 2 days of life				
Opioids	103 (58.2)	135 (73.4)	0.003	0.004
Sustained sedation	40 (22.6)	58 (31.5)	0.06	0.07
Steroids	122 (68.9)	72 (39.1)	<0.001	<0.001
Antibiotics	109 (61.6)	46 (25.0)	<0.001	<0.001
Blood transfusion	7 (4.0)	0 (0.0)	0.006	0.99
Vasopressor agents	14 (7.9)	4 (2.2)	0.02	0.02
Nasoenteric feeding	17 (9.6)	2 (1.1)	<0.001	0.003
Invasive mechanical ventilation	12 (6.8)	1 (0.5)	0.001	0.01
Non-invasive ventilation	28 (15.8)	0 (0.0)	<0.001	0.99
Attempt resuscitation	7 (4.0)	3 (1.6)	0.21	0.21
Infusion volume in the last day of life, mL/day	1000 (500–1350)	500 (200–800)	<0.001	<0.001
Life-sustaining care decision at 48 hours before death	128 (72.3)	176 (95.7)	<0.001	<0.001

Categorical variables are expressed as number (percentage).
Quantitative variables are expressed as median (IQR).
Parameters in each group were compared using Fisher's exact test or Mann-Whitney U test as appropriate.
*To calculate adjusted p values, linear regression models or logistic regression models were used as appropriate. All models were adjusted for patient's age at death and patient's sex.
†The dependent variable, place of death, was handled as a dichotomous variable (ie, hospice or others), and its association with the patient's diagnosis was assessed using a logistic regression model.
ICU, intensive care units; ILD, interstitial lung disease.

and 117 died in the general ward (63.6%). The proportion of opioid administration at the last hospitalisation was significantly lower in patients with ILD versus those with LC (9.6% vs 32.1%; p<0.001). During the last hospitalisation, patients with ILD were significantly less likely to be referred to specialised palliative care services than those with LC (8.5% vs 54.3%; p<0.001). Blood tests and radiographs during the last 7 days of life were frequently performed in patients with ILD versus those with LC (thrice vs once weekly; p<0.001). Comparing the medical interventions performed during the last 2 days of life, patients with ILD were less likely to receive opioids (58.2% vs 73.4%; p=0.003). However, they were more likely to undergo treatment with steroids, antibiotics, blood transfusion, a large volume of infusion and life-prolonging procedures (eg, vasopressor agents, nasoenteric feeding, invasive mechanical ventilation and non-invasive ventilation) than those with LC. Fewer patients with ILD made a life-sustaining care decision at 48 hours prior to death than those with LC (72.3% vs 95.7%; p<0.001).

End-of-life discussion

Details of the end-of-life discussion are summarised in table 3. Most cases in both groups had end-of-life discussion (91.6% vs 95.5%; p=0.36). However, patients with ILD were less likely to participate in end-of-life discussion than those with LC (40.8% vs 62.4%; p=0.007). Patients with ILD and their family members were more likely to discuss 'resuscitation' (66.7% vs 34.1%; p<0.001) and less likely to discuss 'place of death' (14.5% vs 57.3%; p<0.001). In most cases of ILD, end-of-life discussions were initiated by the pulmonologists in an inpatient setting. The first end-of-life discussion was held within 1 month of death in 44% of ILD cases.

Association of QODD with palliative care access and participation in end-of-life discussion

Patients with ILD were divided into the following three groups according to the presence or absence of palliative care access and end-of-life discussion participation: patients without both palliative care access and participation in end-of-life discussion (group A, n=36); patients with either palliative care access or participation in end-of-life discussion (group B, n=27); and patients with both palliative care access and participation in end-of-life discussion (group C, n=13). The GDI score in each group is summarised in figure 4. As the intensity of the interventions of

Table 3 Details of end-of-life discussion

	ILD		Lung cancer			
	Total (n)	n (%)	Total (n)	n (%)	P value	Adjusted p value*
Holding EOL discussion	83	76 (91.6)	89	85 (95.5)	0.36	0.06
Patient participation in EOL discussion	76	31 (40.8)	85	53 (62.4)	0.007	0.004
Topic discussed in EOL discussion	69		82			
Place of death		10 (14.5)		47 (57.3)	<0.001	<0.001
Resuscitation		46 (66.7)		28 (34.1)	<0.001	<0.001
Use of specialist palliative care service		17 (24.6)		30 (36.6)	0.16	0.13
Transfer to other facilities		23 (33.3)		25 (30.5)	0.73	0.81
Provider of the initial EOL discussion	75		84		0.95	0.65†
Pulmonologist		65 (86.7)		75 (89.3)		
Palliative care physician		3 (4.0)		3 (3.6)		
Primary care physician		3 (4.0)		2 (2.4)		
Other		4 (5.3)		4 (4.8)		
Setting where EOL discussion initiated	75		84		0.01	0.01‡
Inpatient		62 (82.7)		55 (65.5)		
Outpatient		10 (13.3)		27 (32.1)		
During home visit service		3 (4.0)		2 (2.4)		
Timing of initiating EOL discussion	74		84		0.17	0.051§
>3 months before the patient's death		20 (27.0)		28 (33.3)		
1–3 months before the patient's death		21 (28.4)		31 (36.9)		
<1 month before the patient's death		33 (44.6)		25 (29.8)		

Each parameter is expressed as number (percentage).
Parameters in each group were compared using Fisher's exact test.
*To calculate adjusted p values, logistic regression models were used. All models were adjusted for patient's age at death and patient's sex.
†The dependent variable, provider of the initial EOL discussion, was handled as a dichotomous variable (ie, pulmonologist or others).
‡The dependent variable, setting where EOL discussion initiated, was handled as a dichotomous variable (ie, pulmonologist or others).
§The dependent variable, timing of initiating EOL discussion, was handled as a dichotomous variable (ie, <1 month before the patient's death or others).
EOL, end of life; ILD, interstitial lung disease.

interest increased, the GDI scores showed a significant monotonic increasing trend (p=0.03, according to the Jonckheere-Terpstra trend test); the GDI scores were the highest for group C (median: 4.65, IQR: 4.24–5.14), followed by group B (median: 4.50, IQR: 3.98–4.81) and group A (median: 4.06, IQR: 3.67–4.68).

DISCUSSION

To the best of our knowledge, this is the first study to explore in detail the differences in QODD and end-of-life interventions between patients with ILD and those with LC through a bereaved family survey and medical chart review. The bereaved family survey revealed that patients with ILD were more likely to suffer from very severe breathlessness and had a lower GDI score for QODD than those with LC, especially in domains related to 'physical and psychological distress relief' and 'prognosis awareness and participation in decision making'. In end-of-life interventions, patients with ILD had poorer access to palliative care despite their distress. Additionally, for more than half of patients with ILD, end-of-life discussions were held in their absence. These findings suggest that patients with ILD face serious problems with symptom relief and decision-making processes.

Our study raised the issue of symptom relief in patients with ILD. In our cohort, patients with ILD were significantly less likely to receive opioids and specialised palliative care services than those with LC, despite experiencing severe breathlessness more often. Moreover, the bereaved family survey showed that the score of the domain related to 'physical and psychological distress relief' in patients with ILD was lower than that obtained for patients with LC. These results suggest that physicians may underestimate patients' needs regarding palliative care, and patients with ILD do not experience sufficient relief from severe symptoms (eg, breathlessness and cough) before death. Severe breathlessness has been reported to be associated with a transition to the hospital at the end of life.[21] Therefore, for patients with ILD who want to die at home, successful management of breathlessness may help fulfil their wishes.[22] Notably, integrated palliative and respiratory care has been shown to improve breathlessness and has the potential to improve psychological outcomes and survival.[23 24] Importantly, healthcare professionals caring for patients with ILD should make efforts to recognise palliative care needs and provide appropriate medical interventions.

Next, we found that patients with ILD were not involved in decision making at end-of-life planning. The present study revealed that more than half of patients with ILD did not participate in their end-of-life discussion. Additionally, patients with ILD had a higher frequency of undecided life-sustaining care plan until immediately prior to death than patients with LC. As a result, the score of the domain related to 'prognosis awareness and participation in decision making' of patients with ILD was lower than that of patients with LC. Several studies have reported that patients with ILD did not have sufficient discussion regarding their prognosis and had a poor understanding of disease behaviour at the end stages and their prognosis.[25 26]

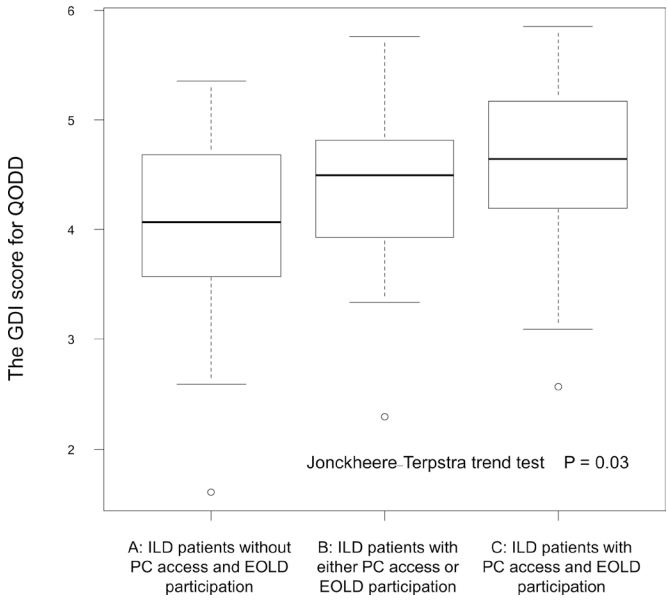

Figure 4 Distribution of QODD in patients with ILD according to the presence or absence of palliative care access and EOLD participation. The upper and lower box sides represent 75th and 25th percentiles, respectively. The thick line indicates the median. QODD domains were measured using GDI. Scores range from 1 to 7 (higher scores indicate higher perceived quality of dying and death). EOLD, end-of-life discussion; GDI, Good Death Inventory; ILD, interstitial lung disease; PC, palliative care; QODD, quality of dying and death.

Prognostication in patients with ILD is uncertain and more difficult than in patients with cancer. Especially, acute exacerbation, which was the most common cause of death in patients with ILD in our cohort, is life-threatening and unpredictable. These aspects would make it difficult for physicians to explain disease progression to patients with newly diagnosed or stable ILD. However, both patients with ILD and family members wished to receive more information from physicians.[26] Therefore, sharing disease information, including disease behaviour and also 'uncertainty in prognosis', among physicians, patients and their families may increase understanding of ILD and awareness of prognosis and promote advance care planning.

Our study showed lower frequencies of 'access to palliative care' and 'participation of patients themselves in end-of-life discussion' in patients with ILD versus those with LC. These findings are generally consistent with previous reports,[4 25 27] suggesting that implementing these interventions is an important concern for patients with ILD, regardless of region or culture. In patients with cancer, specialised palliative care referral has been associated with higher QODD.[16 17] Additionally, patients with advanced cancer who participated in the decision-making process and had an awareness of the terminal illness had higher QODD than those who did not.[18 19] Hence, we explored the association of QODD with palliative care access and participation in end-of-life discussion in patients with ILD. As expected, the implementation of these interventions was associated with higher QODD. Therefore, providing palliative care and promoting patient participation in end-of-life discussion may lead to improved QODD in this setting. A multidisciplinary team approach may assist in these efforts. Barratt and colleagues[28] recently reported that a multidisciplinary team meeting among a palliative physician, a psychologist and an ILD specialist resulted in a significant increase in specialist palliative care referral and advance care planning discussions. Further investigation is warranted to examine the effectiveness of these measures and develop better interventions for patients with ILD and their family members.

This study has several mentionable limitations. First, the present study was conducted in a limited area of Japan, and the number of bereaved survey participants was relatively small. A nationwide survey should be conducted to confirm these results. Second, we enrolled patients who died in hospitals or inpatient hospices belonging to the hospitals and excluded those who died at home or a nursing facility. Thus, we could not exclude the potential for selection bias. However, most patients with ILD die in the hospital,[29 30] and approximately 80% of patients terminally ill with cancer died in acute care hospitals in Japan,[31] suggesting that this bias is unlikely to influence the conclusion. Third, there is bias associated with selection, recall, proxy and missing data in the bereavement survey. A careful interpretation after integrating other results is warranted. Fourth, medical records contain data that are only recorded by healthcare professionals. Recording practices may vary among different professionals, which could have influenced the findings. Fifth, although we tried to address confounding, residual bias might have influenced the findings. Sixth, there are some concerns about whether the comparisons with patients with LC were the best comparisons. A study comparing ILD with other diseases, such as COPD, whose clinical course is as difficult to predict as that of ILD, is warranted.

In conclusion, this study showed that patients with ILD had lower QODD than those with LC, and the domains related to 'physical and psychological distress relief' and 'prognosis awareness and participation in decision making' were especially lower. Patients with ILD had poorer access to palliative care despite their distress. Furthermore, patients with ILD had a lower frequency of patient participation in end-of-life discussions. These findings suggests that patients with ILD have insufficient distress relief and are not well informed. Therefore, more efforts to improve QODD in patients with ILD, particularly in symptom relief and the decision-making processes, are urgently required. Although further investigation is warranted, our study highlights the necessary improvement to achieve a good death in patients with ILD.

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Patient consent for publication Not required.

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Data availability statement Participants of this study did not agree for their data to be shared publicly, so supporting data are not available.

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Quality of dying and death in patients with interstitial lung disease compared with lung cancer: an observational study

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eMETHODS

Measurements

Symptom Burden at the End-of-life

Symptom burden at end-of-life was quantified using the Memorial Symptom Assessment Scale (MSAS), which is a brief measure of patient global symptom burden [1]. The MSAS was validated to measure the psychological and physical symptom burden from the perspective of the bereaved family [2]. Bereaved family members were asked to rate the seven physical symptom burden experienced by patients in the last 2 days of life. The responses of the bereaved family members were graded from "0: not at all," "1: trivial," "2: mild," "3: severe," or "4: very severe."

Quality of Dying and Death.

Quality of dying and death (QODD) was quantified using the Good Death Inventory (GDI), which is a validated and reliable tool for measuring QODD from the perspective of the bereaved family (**Supplemental Table E1**) [3–5]. The GDI was developed based on qualitative interviews and a quantitative study of bereaved family members of deceased patients with cancer. It consists of 18 domains, including 10 core and eight optional domains. Bereaved family members were asked to rate the patient's QODD in their final places of care using a seven-point Likert-type scale. Higher values indicated higher QODD.

Quality of Care

Family-perceived quality of care (QOC) was quantified using the short version of the Care Evaluation Scale (CES), which is a validated and reliable tool for measuring the quality of the structure and processes of end-of-life care from the perspective of the bereaved family [6]. The CES consists of 10 domains. The short version of the CES consists of 10 representative items from each of these domains. Bereaved family members were asked to rate the QOC in their final places using a six-point Likert-type scale. The average score across all 10 domains was used to evaluate the overall QOC, with higher values indicating better care.

Interventions at End-of-life

Clinical data on treatment and care were obtained from the medical records by one of the investigators. We collected information regarding interventions associated with aggressive treatment or end-of-life medical care [7–12]. The collected information included: a place of death; referral to specialized palliative care services during the last hospitalization; a number of radiographs and blood tests during the last 7 days of life; administration of opioids, sustained sedation (i.e., continuous use of midazolam or propofol), steroids, antibiotics, blood transfusion, vasopressor agents, nasoenteric feeding, invasive mechanical ventilation, non-invasive ventilation, and cardiopulmonary resuscitation during the last 2 days of life; infusion volume in the last day of life; life-sustaining care decisions at 48 h prior to death (i.e., presence of a do-not-resuscitate order at 48 h prior to death in the medical record).

End-of-life Discussion

We requested the families to report whether patients and the bereaved family members had participated in end-of-life discussions. In case of positive response, we asked whether the following topics were discussed: the place of care (e.g., inpatient hospice or home); cardiopulmonary resuscitation; use of specialist palliative care services; and transfer to another facility (e.g., local long-term care facilities). We also enquired about the providers of the initial end-of-life discussion (i.e., pulmonologist, palliative care physician, primary care physician, or others), setting (i.e., inpatient, outpatient, during home visit service), and timing (i.e., >3, 1–3, or <1 month prior to the death of the patient) [13].

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Supplemental Table E1. Good Death Inventory (GDI)

How do you think the patient felt during the end-of-life period? Please place the appropriate number next to each statement: 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree.

I. Physical and psychological comfort	**II. Dying in a favourite place**
Patient was free from pain.	Patient was able to stay at his or her favorite place.
Patient was free from physical distress.	Patient was able to die at his or her favorite place.
Patient was free from emotional distress.	The place of death met the preference of the patient.
III. Maintaining hope and pleasure	**IV. Good relationship with medical staff**
Patient lived positively.	Patient trusted the physician.
Patient had some pleasure in daily life.	Patient had a professional nurse with whom he or she felt comfortable.
Patient lived in hope.	Patient had people who listened.
V. Not being a burden to others	**VI. Good relationship with family**
Patient was not being a burden to others (*).	Patient had family support.
Patient was not being a burden to family members (*).	Patient spent enough time with his or her family.
Patient had no financial worries (*).	Patient had family to whom he or she could express feelings.
VII. Independence	**VIII. Environmental comfort**
Patient was independent in moving or waking up.	Patient lived in quiet circumstances.
Patient was independent in daily activities.	Patient lived in calm circumstances.
Patient was not troubled with excretion.	Patient was not troubled by other people.
IX. Being respected as an individual	**X. Life completion**
Patient was not treated as an object or a child.	Patient had no regrets.
Patient was respected for his or her values.	Patient felt that his or her life was completed.
Patient was valued as a person.	Patient felt that his or her life was fulfilling.
XI. Receiving enough treatment	**XII. Natural death**
Patient received enough treatment.	Patient was not connected to medical instruments or tubes.
Patient believed that all available treatments were used.	Patient did not receive excessive treatment.
Patient fought against disease until the last moment.	Patient died a natural death.
XIII. Preparation for death	**XIV. Control over the future**
Patient met people whom he or she wanted to see.	Patient knew how long he or she was expected to live.
Patient felt thankful to people.	Patient knew what to expect about his or her condition in the future.
Patient was able to say what he or she wanted to dear people.	Patient participated in decisions about treatment strategy.
XV. Unawareness of death	**XVI. Pride and beauty**
Patient died without awareness that he or she was dying.	Patient felt burden of a change in his or her appearance (*).
Patient lived as usual without thinking about death.	Patient felt burden of receiving pity from others (*).
Patient was not informed of bad news.	Patient felt burden of exposing his or her physical and mental weakness to family (*).
XVII. Feeling that one's life is worth living	**XVIII. Religious and spiritual comfort**
Patient felt that he or she could contribute to others.	Patient was supported by religion.
Patient felt that his or her life is worth living.	Patient had faith.
Patient maintained his or her role in family or occupation.	Patient felt that he or she was protected by a higher power.

(*) Inverse items.

Supplemental Table E2. Characteristics of ILD patients with or without questionnaire response

	Respondents, ILD n = 83	**Nonrespondents, ILD** n = 94	P value
Age, years	75.4 (8.7)	76.6 (8.0)	0.36
Sex			0.11
Male	69 (83.1)	68 (72.3)	
Female	14 (16.9)	26 (27.7)	
LTOT, yes	45 (54.2)	47 (50.0)	0.65
Type of disease			0.77
IPF	37 (44.6)	41 (43.6)	
Non-IPF IIP	26 (31.3)	32 (34.0)	
CTD-IP	18 (21.7)	18 (19.1)	
CHP	2 (2.4)	1 (1.1)	
Others	0 (0.0)	2 (2.1)	
Cause of death			0.49
Acute exacerbation	49 (59.0)	50 (53.2)	
Exacerbation of chronic respiratory failure	22 (26.5)	27 (28.7)	
Respiratory infection	8 (9.6)	7 (7.4)	
Others	4 (4.8)	10 (10.7)	
Months from diagnose to death	35 (9-76)	28 (5-55)	0.18
Place of death			0.60
General ward	79 (95.2)	89 (94.7)	
ICU	3 (3.6)	5 (5.3)	
Hospice	1 (1.2)	0 (0.0)	

Categorical variables were expressed as number (percentage). Quantitative variables were expressed as mean (SD) or median (IQR). Fisher's exact test was used to analyse categorical variables, and the Student's *t*-test or the Mann–Whitney *U* test was used to analyse quantitative variables as appropriate.

ILD, interstitial lung disease; LTOT, long-term oxygen therapy; IPF, idiopathic pulmonary fibrosis; Non-IPF IIP, idiopathic interstitial pneumonia excluding idiopathic pulmonary fibrosis; CTD-IP, connective tissue disease-related interstitial pneumonia; CHP, chronic hypersensitivity pneumonitis; ICU, intensive care units; SD, standard deviation; IQR, interquartile range.

Supplemental Table E3. Characteristics of lung cancer patients with or without questionnaire response

	Respondents, Lung cancer n = 89	**Nonrespondents, Lung cancer** n = 95	P value
Age, years	74.8 (11.0)	75.0 (8.3)	0.89
Sex			0.62
Male	67 (75.3)	68 (71.6)	
Female	22 (24.7)	27 (28.4)	
LTOT, yes	15 (16.9)	14 (14.7)	0.84
Type of disease			0.35
Adenocarcinoma	45 (50.6)	48 (51.1)	
Squamous-cell carcinoma	18 (20.2)	17 (18.1)	
Small cell carcinoma	8 (9.0)	17 (18.1)	
Clinical diagnosis	10 (11.2)	6 (6.4)	
Others	8 (9.0)	6 (6.4)	
Cause of death			0.30
Cancer progression	87 (97.8)	93 (97.9)	
Treatment-related death	2 (2.2)	0 (0.0)	
Infection	0 (0.0)	1 (1.1)	
Others	0 (0.0)	1 (1.1)	
Months from diagnose to death	11 (5-23)	10 (3-31)	0.79
Place of death			0.29
General ward	53 (59.6)	64 (67.4)	
ICU	0 (0.0)	0 (0.0)	
Hospice	36 (40.4)	31 (32.6)	

Categorical variables were expressed as number (percentage). Quantitative variables were expressed as mean (SD) or median (IQR). Fisher's exact test was used to analyse categorical variables, and the Student's *t*-test or the Mann–Whitney *U* test was used to analyse quantitative variables as appropriate.

LTOT, long-term oxygen therapy; ICU, intensive care units; SD, standard deviation; IQR, interquartile range.

Supplemental Table E4. Good Death Inventory domain scores for quality of dying and death among ILD and lung cancer patients

	ILD		**Lung cancer**		Effect size		Adjusted
	Means	SD	Means	SD	(Hedges)	P value	p value*
Quality of dying and death (average of 18 domains of GDI)	4.33	0.82	4.57	0.70	-0.31	0.04	0.02
Score of each domain							
Physical and psychological comfort	3.99	1.64	4.59	1.51	-0.38	0.02	0.01
Dying in a favourite place	4.35	1.63	4.57	1.48	-0.14	0.36	0.24
Maintaining hope and pleasure	3.74	1.47	3.95	1.34	-0.15	0.35	0.23
Good relationship with medical staff	5.12	1.18	5.36	0.97	-0.22	0.15	0.08
Not being a burden to others	3.99	1.52	4.10	1.23	-0.08	0.59	0.66
Good relationship with family	4.84	1.22	4.98	0.93	-0.13	0.40	0.45
Independence	3.75	1.76	3.70	1.83	0.03	0.84	0.92
Environmental comfort	4.67	1.46	5.09	1.26	-0.31	0.048	0.02
Being respected as an individual	5.54	1.24	5.75	0.90	-0.19	0.20	0.09
Life completion	4.08	1.69	4.28	1.44	-0.13	0.39	0.17
Receiving enough treatment	4.94	1.43	5.15	1.04	-0.17	0.28	0.17
Natural death	4.87	1.28	5.23	1.08	-0.30	0.052	0.03
Preparation for death	4.76	1.55	4.78	1.10	-0.01	0.91	0.90
Control over the future	4.19	1.65	4.71	1.29	-0.35	0.02	0.02
Unawareness of death	3.81	1.34	3.95	1.30	-0.11	0.48	0.35
Pride and beauty	3.71	1.16	3.81	1.14	-0.09	0.59	0.72
Feeling that one's life is worth living	5.24	1.37	5.33	1.08	-0.07	0.67	0.58
Religious and spiritual comfort	2.62	1.89	2.80	1.59	-0.10	0.51	0.78

Good Death Inventory domain scores range 1 to 7; higher scores indicate a higher perceived quality of dying and death. The Student's *t*-test was used to analyse quantitative variables. We calculated the effect size (Hedges' g) to evaluate the size of these differences. *To calculate adjusted p values, linear regression models were used. All models were adjusted for patient's age at death, patient's sex, age of the family member, and the relationship between the patient and the family.

ILD, interstitial lung disease; SD; standard deviation; GDI, Good death Inventory.

Supplemental Table E5. Care Evaluation Scale domain scores for family-perceived quality of care among ILD and lung cancer patients

	ILD		**Lung cancer**		Effect size		Adjusted
	Means	SD	Means	SD	(Hedges)	P value	p value*
Quality of care (average of 10 domains of CES)	4.46	0.77	4.72	0.63	-0.37	0.02	0.01
Score of each domain							
Physical care by physician	4.50	1.09	4.81	0.74	-0.33	0.03	0.02
Physical care by nurse	4.54	0.77	4.73	0.83	-0.24	0.12	0.047
Psycho-existential care	4.37	1.12	4.83	0.93	-0.45	0.004	0.003
Physician's explanation to the patient	4.40	1.51	4.80	0.97	-0.32	0.04	0.03
Physician's explanation to the family	4.75	1.25	4.94	0.85	-0.18	0.23	0.15
Environment	4.18	1.00	4.70	0.85	-0.56	<0.001	<0.001
Cost	3.73	1.07	4.21	1.07	-0.45	0.004	0.001
Consideration of family health	4.56	0.96	4.65	0.72	-0.11	0.49	0.29
Availability	5.11	0.99	4.92	1.00	0.19	0.22	0.24
Coordination and consistency	4.49	1.14	4.62	0.89	-0.13	0.42	0.37

Care Evaluation Scale domain scores range 1 to 6; higher scores indicate a higher perceived quality of care. The Student's t-test was used to analyse quantitative variables. We calculated the effect size (Hedges' g) to evaluate the size of these differences. *To calculate adjusted p values, linear regression models were used. All models were adjusted for patient's age at death, patient's sex, age of the family member, and the relationship between the patient and the family.

ILD, interstitial lung disease; SD; standard deviation; CES, Care Evaluation Scale.