

Palliative care for idiopathic pulmonary fibrosis patients: Pulmonary physicians' view

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28 **Abbreviations:**

29 ES, effect size; ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis; SD, standard deviation.

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55 **ABSTRACT**

56 Background and objective: Though idiopathic pulmonary fibrosis (IPF) has worse outcomes compared
57 to most malignancies, patients with IPF receive poor access to optimal palliative care. This study aimed
58 to characterise the practice of pulmonologist's regarding palliative care and end of life communication
59 for patients with IPF and identify perceived difficulties and barriers thereto.

60 Methods: Self-administered questionnaires were sent by mail to representative pulmonologists from
61 Shizuoka prefecture, Japan. Physician-reported practice, difficulties, timing of end of life
62 communication and barriers related to palliative care were investigated.

63 Results: Among the 135 participants, 130 (96%) completed the questionnaire. Most of the participants
64 reported that patients with IPF complained of dyspnoea and cough. However, less morphine was
65 prescribed for IPF than for lung cancer. The participants experienced greater difficulty in providing
66 palliative care for IPF than for lung cancer. Moreover, actual end of life discussions in patients with IPF
67 were conducted later than the physician-perceived ideal timing. Among the barriers identified, few
68 established treatment and difficulty in predicting prognosis [odds ratio (OR) 2.0; $p = 0.04$],
69 discrepancies in understanding and care goals among patients, family and medical staff (OR 2.2; $p =$
70 0.03) and inadequate communication about goal of care (OR 2.3; $p = 0.003$) were significantly
71 associated with the physician-perceived difficulties in providing palliative care for patients with IPF.

72 Conclusions: Pulmonologists experienced greater difficulty in providing palliative care to patients with
73 IPF than to those with lung cancer. Clinical studies on the optimal palliative care for patients with IPF
74 are urgently required.

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82 **Key Message:** Pulmonologists experienced greater difficulty in providing palliative care to patients with
83 IPF than to those with lung cancer. Clinical studies on the optimal palliative care for patients with IPF
84 are urgently required.

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86 **Keywords:** advance care planning; end of life care; idiopathic pulmonary fibrosis; palliative care

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88 **Running Title:** Palliative care for idiopathic pulmonary fibrosis patients

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109 INTRODUCTION

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111 Idiopathic pulmonary fibrosis (IPF) is the most prevalent fibrotic interstitial lung disease (ILD), which
112 has worse outcomes than most malignancies with a mean survival period from diagnosis ranging from 2
113 to 3 years.¹⁻⁵ Patients with IPF have been challenging to manage given that few medical therapies have
114 shown any survival benefit, while lung transplantation remains the only option to improve survival.¹⁻⁶
115 Palliative care is thus an important consideration for patients with IPF.

116 The World Health Organization (WHO) recommends early palliative care to ‘improve the quality of life
117 of patients and their family facing the problem associated with life-threatening illness, through the
118 prevention and relief of suffering by means of early identification and impeccable assessment and
119 treatment of pain and other problems, physical, psychosocial and spiritual’.⁷ Patients with IPF suffer
120 from high symptom burden and poor quality of life as the disease progresses.¹⁻⁵ IPF is characterised by
121 dyspnoea, cough, anxiety and depression and most patients with IPF ultimately need supplemental
122 oxygen therapy.¹⁻⁵ The need for palliative care often increases as the disease progresses. Accordingly,
123 studies have shown that palliative care needs of patients with IPF and their caregivers are not inferior to
124 those with malignancies.^{8,9} Although the current IPF guidelines recommend palliative care and
125 symptom-based approach as an adjunct to disease-focused care³, most patients with IPF do not receive
126 optimal palliative care throughout the course of the disease or even at the end of life.^{10,11,12}

127 Preliminary studies on a small number of specific individuals, i.e. patients receiving lung
128 transplantation, suggest various reasons for why patients with IPF do not receive optimal palliative care,
129 including fear that discussions regarding end of life care will diminish the patients’ hope, physician
130 discomfort, inclusion of caregivers and family members during discussions^{13,14} and physician
131 uncertainty regarding palliative care administration.¹¹ Although narrative reviews have listed several
132 barriers to the provision of optimal palliative care for patients with IPF^{15,16}, to our knowledge, no study
133 has systemically investigated the physician’s view on barriers to optimal palliative care for patients with
134 IPF and how such barriers affect their daily practice.

135 We thus developed a survey that would characterise the practice of Japanese pulmonologist’s regarding

136 palliative care and end of life communication for patients with IPF and identify perceived difficulties
137 and barriers thereto.

138

139 **METHODS**

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141 **Participant recruitment and procedure**

142 The self-administered questionnaires were sent by mail to a representative sample of pulmonologists and
143 fellows of pulmonary medicine working in the Shizuoka prefecture, Japan, between December 2018 and
144 March 2019. In this region, the Hamamatsu University School of Medicine utilized 15 general hospitals
145 as training facilities, and it accounts for 78.9%, 15 of all 19 hospitals with a pulmonary division in this
146 region; and centrally managed information of all physicians working at 15 hospitals. We thus obtained
147 a list of all 135 pulmonologists and fellows of pulmonary medicine from the university. Physicians who
148 had clinical experience within the previous year were eligible for this survey. The participants were
149 asked to return the questionnaire within 4 months. No compensation was provided.

150

151 **Questionnaire development**

152 The self-administered questionnaire utilised herein was developed based on a review of the literature.¹²⁻
153 ²¹ The study group, which consisted of one palliative care specialist and five pulmonologists, developed
154 the questionnaire to ensure clarity and comprehensiveness. Face validity was confirmed with a pilot test
155 on 15 pulmonologists.

156 The survey questionnaire included (1) current practice of palliative care for patients with IPF (10
157 questions); (2) physician-perceived difficulties in providing palliative care for patients with IPF and lung
158 cancer (5 questions); (3) optimal and actual timing of end of life communication between patients with
159 IPF and attending physicians (2 questions) and (4) perceived barriers to palliative care for patients with
160 IPF (37 questions). The respondents were requested to rate their agreement with each question on a 5-
161 point Likert scale (1, not at all; 2, rarely; 3, occasionally; 4, often; and 5, always). For the questions
162 regarding optimal timing of end of life communication, the respondents were requested to select one

163 answer from seven choices ranging from ‘at the time of diagnosis’ to ‘do not discuss’. For questions
164 concerning barriers, the respondents were requested to rate their agreement with each barrier on a 5-
165 point Likert scale (1, not a barrier at all; 2, minimal barrier; 3, moderate barrier; 4, large barrier; 5, huge
166 barrier) reference. The following data were also collected to characterise the participants: age, gender,
167 years of practice, type of hospital and number of patients with ILD and IPF treated per year. Experience
168 with the national palliative care education programme (i.e. the PEACE programme) was also recorded.²²

169

170 **Statistical analysis**

171 All returned questionnaires were analysed. The frequencies and percentages of eligible participants’
172 responses to each item were calculated. Student t-tests were used to compare perceived difficulties to
173 palliative care for IPF and lung cancer, while Mann–Whitney *U* tests were employed to compare the
174 results of ideal vs. actual timing of communication. Based on a previous study, barriers were considered
175 significant when the sum of the percentage for ‘large barrier’ and ‘huge barrier’ was more than 60% in
176 questions regarding barriers to palliative care.¹⁴ To summarise the data, questions regarding barriers
177 were categorised into six subscales based on exploratory factor analyses with varimax rotation and
178 Cronbach’s alpha coefficient calculation. A total of 21 barriers from the initial 34 barriers were further
179 analysed. Mean subscale scores for each item were calculated, with higher scores indicating a higher
180 perceived barrier. To explore determinants of physician’s attitudes, the six barrier subscales were
181 analysed through regression analysis using the physician-perceived difficulty score as the independent
182 variable and barrier variables as the explanatory variable while adjusting for physician demographic
183 factors, such as clinical experience and age. All statistical analyses were performed using EZR (Saitama
184 Medical Center, Jichi Medical University, Saitama, Japan), a graphical user interface for R (The R
185 Foundation for Statistical Computing, Vienna, Austria)²³, with statistical significance being set at $p <$
186 0.05.

187 This study was approved by the Hamamatsu University School of Medicine Ethics Board, Hamamatsu,
188 Japan (18-214). Consent was assumed by the completion of the survey.

189

190 **RESULT**

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192 **Participant characteristics**

193 Among the 135 eligible participants, 130 completed the questionnaire (participation rate of 96.3%). The
194 characteristics of participants are summarised in Table 1. Most participants (98.5%) had cared for at
195 least one patient with IPF within the last year.

196

197 **Practice of palliative care for patients with IPF**

198 Among the participants, 93% and 83% stated that patients with IPF often or always complained of
199 dyspnoea and cough, respectively (Table 2). In addition, 79% reported the patients had anxiety or
200 depression occasionally, often, or always; while the number of the IPF patients who complained of pain
201 was less than 20%. For the management of cough, 74.6% used dextromethorphan, while 19.2% used
202 morphine. Majority of the participants (73%) stated that they had occasionally or often discussed about
203 end of life care with patients with IPF. However, approximately 70% of the participants reported that
204 end of life care was only discussed with the family excluding the patient and that information given to
205 the patients or family members was occasionally or often changed, i.e., the different levels of
206 information are provided to patients vs family (Table 2).

207

208 **Difficulty in providing palliative care for patients with IPF and lung cancer**

209 As shown in Figure 1, physicians found it significantly more difficult to provide palliative care to
210 patients with IPF than to patients with lung cancer [IPF 3.7, standard deviation (SD), 0.85 vs. lung
211 cancer 2.9, SD: 0.85; effect size (ES), 0.94; $p < 0.001$]. Among the participants, 70% reported that they
212 ‘always’ or ‘frequently’ experienced difficulty in providing palliative care to patients with IPF, with
213 31.5% answering ‘occasionally’ and 8.5% answering ‘rarely’ (Figure 1). Moreover, physicians were
214 significantly less likely to use opioids for dyspnoea on exertion (IPF 2.55, SD: 0.92 vs. lung cancer 3.99,
215 SD: 1.03; ES, 1.47; $p < 0.001$) and for dyspnoea at rest (IPF 2.77, SD: 0.95 vs. lung cancer 4.18, SD:

216 0.94; ES, 1.49; $p < 0.001$) in patients with IPF than in those with lung cancer (Figure 1).

217

218 **Ideal and actual timing of end of life communication with patients having IPF**

219 Actual end of life discussions with patients were conducted significantly later than the physician-
220 perceived ideal timing for the same ($p < 0.001$) (Figure 2). Approximately half of the participants

221 (46.9%) stated that the ideal timing was during initiation of home oxygen therapy, followed by

222 hospitalisation due to acute exacerbation of IPF (19%) and upon diagnosis of IPF (10%) (Figure 2).

223 However, the actual timing of end of life discussions occurred during hospitalisation due to acute

224 exacerbation (59.1%), followed by initiation of home oxygen therapy (20%) and upon diagnosis of IPF

225 (3.6%) (Figure 2).

226

227 **Barriers to palliative care for patients with IPF**

228 Barriers to palliative care were identified across six domains (Table 3), with the greatest number of

229 barriers identified under the ‘few established treatment and difficulty in predicting prognosis’ and

230 ‘discrepancies in understanding and care goals among patients, family and medical staff’ subscales. Few

231 established treatment to relieve the symptoms (71.6%), difficult to predict the prognosis or disease

232 progression (66.9%), few established treatment to improve survival (66.1%) and disagreements between

233 family and patient about care goals (60.0%) were highlighted as significant physician-perceived barriers

234 for providing palliative care to patients with IPF.

235

236 **Determinants of physician-reported difficulties: association between perceived barriers**

237 With regard to respondent background, younger age, type of facility (small) and larger number of ILD

238 deaths per year were significantly associated with the difficulty in providing palliative care for patients

239 with IPF (data not shown). Figure 3 demonstrates the results of nominal logistic regression analysis after

240 adjusting for respondent background (age, type of facility and number of ILD deaths per year).

241 Accordingly, ‘few established treatment and difficulty in predicting prognosis’ [odds ratio (OR) 2.0; $p =$

242 0.04], ‘discrepancies in understanding and care goals among patients, family and medical staff’ (OR 2.2;

243 p = 0.03) and ‘inadequate communication about goal of care’ (OR 2.3, p = 0.003) were significantly
244 associated with difficulty in providing palliative care for patients with IPF.

245

246 **DISCUSSION**

247

248 To our knowledge, this has been the first study to systemically investigate the clinical practice,
249 difficulties and perceived barriers related to palliative care for patients with IPF from the perspective of
250 respiratory physicians.

251 One important finding of the present study was that physicians felt greater difficulty in providing
252 palliative care for patients with IPF than for those with lung cancer. A possible interpretation is that
253 palliative care for patients with IPF is predominantly provided by respiratory physicians in Japan, and
254 team approach including respiratory nurse, psychologists, and palliative care team is uncommon
255 compared with in case of cancer patients. An epidemiological study revealed that patients with IPF
256 received lower rates of palliative care than those with lung cancer.¹¹ Moreover, a recent study revealed
257 that only 13.7% of patients with IPF had been referred to specialised palliative care services, a majority
258 of whom (71%) were referred within 1 month of their death.¹⁰ These findings indicate that multifaceted
259 interventions to improve access to palliative care for patients with IPF urgently needed.

260 Another important finding was the clarification of the three main areas that needed improvement. These
261 barriers identified in this study are generally consistent with previous studies^{8-12,15,16,21}, while almost all
262 (91.5%) respondents had received basic palliative care education programme. This strongly indicates
263 mandatory education alone is less likely to completely overcome the barriers for implementation of
264 palliative care.

265 First, although physicians very frequently experienced dyspnoea and cough, opioids were used less
266 frequently in patients with IPF than in those with cancer. Moreover, the lack of an established treatment
267 for symptom relief was one of the most important barriers participating physicians perceived and was
268 significantly associated with their perceived difficulty in providing palliative care for patients with IPF.

269 These findings are consistent with an empirical study in which patients with IPF experienced lesser

270 improvement in symptoms, such as dyspnoea, despite intensive palliative treatment compared to those
271 with lung cancer.¹¹ To the best of our knowledge, only a few well-designed clinical trials have
272 demonstrated the efficacy of pharmacological therapy in relieving dyspnoea among patients with IPF.²⁴
273 Thus, well-designed clinical trials that could establish medical treatment for dyspnoea relief in patients
274 with IPF are of great value.

275 Second, this study revealed the difficulties in initiating end of life discussion with patients suffering
276 from IPF. The survey indicated that end of life discussions were initiated later than ideally perceived by
277 the physicians, although no observable difference in the frequencies of discussion regarding incurability
278 and DNAR was found between patients with IPF and cancer. One probable reason of this phenomena
279 could be the difficulty in predicting the prognosis of patients with IPF. Accordingly, our results showed
280 that the difficulty in predicting disease progression was significantly associated with the difficulty in
281 providing palliative care for patients with IPF. In cancer, on the other hand, multiple prognostic
282 evaluation models are validated and available for clinical use to identify the appropriate timing for
283 initiating end of life discussion.^{25,26} Further studies are thus needed to develop a clinical model that
284 could predict disease progression and survival and to identify the appropriate timing for end of life
285 discussions among patients with IPF. On the other hand, prognosis itself is not an essential part of
286 palliative care defined the WHO⁷ and thus clinicians should note the role of prediction of patient
287 prognosis does not mean that palliative care should not be provided to patients with better prognosis.

288 Third, inadequate and difficult communication in this population is another important barrier
289 significantly association with physician difficulties. Although empirical research regarding
290 communication issues in patients with IPF has been far limited, a recent small study revealed a
291 discrepancy between the needs of the patients and medical staff such that patients with IPF and their
292 families considered end of life or palliative care as important information, whereas medical staff failed
293 to emphasise the same.²⁷ Inadequate, late and poor communication between patients and physicians have
294 been well recognised in serious illnesses, such as advanced cancer and COPD, contributing to the
295 suffering patients and family members endure.²⁸⁻³¹ Recent multiple randomised controlled trials to
296 improve end of life communication have demonstrated that a structured intervention resulted in more,

297 earlier and better conversations and improved patient outcomes.³²⁻³⁹ With regard to patients with IPF,
298 however, we believe that empirical studies regarding understanding the patient's view of their illness,
299 patient's preferences, prognostic information and goals of care have been very premature. As such, more
300 studies are undoubtedly needed.

301 Cultural aspects should be considered in an interpretation. This survey revealed that end-of-life decision
302 making was often performed only with families without patient involvement, and levels of information
303 were changed to patients vs families. The percentages of the Japanese physicians who reported they often
304 or always made decision making only with family excluding the patients was 35% in this survey vs. 8.1%
305 in Portugal survey; and those who reported they often or always changed the levels of information to
306 patients vs families was 30% in this survey vs. 1.4% in Portugal survey¹⁸. This tendency has been
307 traditionally regarded as family-centered decision making in East Asian culture. In the land-mark study
308 conducted in 2000 to compare physicians' attitude toward patient autonomy⁴⁰, only 17% of Japanese
309 physicians agreed that the patient should be first told and then the family (i.e., usually family first, then
310 patients). The corresponding figures of U.S. physicians in the 2000 survey were 80%. In 2015 survey,
311 however, these figures in Japanese, Korean, and Taiwanese physicians were around 80%, and being very
312 close to those of U.S. physicians in the 2000 survey⁴¹. Patient autonomy is thus increasingly acknowledged
313 in East Asian culture especially in the situation of malignancy. On the other hand, the cross-cultural survey
314 indicated that half of the Japanese, Korean, and Taiwanese physicians maintained that they should not
315 disclose bad news to patients if the family disagrees. In East Asia, the family-centered style in end-of-life
316 decision making was and is still in part major, but the situation is rapidly changing such as rapid spread
317 of patient-centered advance care planning⁴². Careful observation is needed to determine what physician
318 behaviors are regarded as being culturally norm or helpful in end-of-life communication in East Asian
319 context.

320 The strengths of the present study include the high response rate (96.3%) and representativeness of the
321 sample (covered 78.9% of all pulmonary physicians within the prefecture).

322 Some limitations of the present study are worth noting. First, considering that this study was a physician
323 survey, patient and family views had not been investigated. Future studies involving patients with IPF

324 and their family could obtain more insight regarding palliative care for IPF. Second, this survey was
325 conducted in one prefecture in Japan, which might not always be representative of a national sample.
326 Third, given that barrier questionnaires were adopted from previous studies on intensive care settings¹⁷,
327 there might be a lack of factors that other pulmonologists specifically consider important. Forth, we did
328 not adopt open-ended questions or qualitative approach, resulting in lack of opportunity to obtain
329 complex input. Fifth, some respondents actually treated limited number of patients with IPF. Finally,
330 clinical practice related to non-respiratory symptoms, such as psychological distress and pain, were not
331 investigated.

332

333 **CONCLUSIONS**

334 Pulmonary physicians experienced greater difficulty in palliative care for patients with IPF than that for
335 patients with lung cancer. As such, well-designed studies aimed towards establishing appropriate
336 medical treatment for dyspnoea relief in patients with IPF, developing a prognostic model to identify the
337 appropriate timing for initiating end of life discussion and determining the efficacy of communication
338 interventions are urgently required.

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343 **DISCLOSURE STATEMENT:**

344 **Authorship**

345 N.A., T.F. and T.M. contributed to the study concept; N.A., T.F., Y.N., N.I. and T.S. designed the
346 research; N.A., T.F., H.Y., H.H., Y.S., M.K., K.F., N.E., Y.N., N.I. and T.S. contributed to the acquisition
347 of the data; K.M. and T.M. contributed to data analysis; N.A., T.F. and T.M. wrote the initial and final
348 drafts of the manuscript; N.A., T.F., T.M., H.Y., H.H., Y.S., M.K., K.F., N.E., Y.N., N.I. and T.S. revised
349 the drafts of the manuscript; and all authors approved the final version of the manuscript.

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353 **Declaration of conflicts of interest**

354 The authors declare that there is no conflict of interest.

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Tables

Table 1. Participant characteristics.

	All participants (n = 130)
Sex	
male	114 (87.7)
female	16 (12.3)
Age	
20s	18 (13.8)
30s	54 (41.5)
40s	34 (26.2)
50s	19 (14.6)
60s	5 (3.8)
Years of practice (median, range)	12.5 (1–42)
Type of hospital	
University hospital	30 (23.1)
General hospital > 500 beds	73 (56.2)
General hospital < 500 beds	27 (20.8)
Experience with the national palliative care education programme	119 (91.5)
Number of ILD patients cared in the last year	
0	0
1–4	11 (8.5)
5–9	15 (11.5)
>10	104 (80)
Number of IPF patients cared for within the last year	
0	2 (1.5)
1–4	53 (40.8)
5–9	41 (31.5)
>10	34 (26.2)
Number of ILD patients who died within the last year	
0	21 (16.2)
1–4	83 (63.8)
5–9	20 (15.4)
>10	6 (4.6)
Number of IPF patients died in the last year	
0	44 (33.8)
1–4	79 (60.8)
5–9	7 (5.4)
>10	0

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S.D.: standard deviation, ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis

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Table 2. Current status of palliative care for patients with IPF.

Frequency of IPF symptoms: how often patients complained	Never	Rarely	Occasionally	Often	Always
Dyspnoea	0	0	6.9	71.5	21.5
Cough	0	0	16.9	67.7	15.4
Anxiety/depression	1.5	20.0	60.8	16.2	1.5
Pain	19.2	53.8	15.4	0.8	0.8
Frequency of end-of-life communication					
How often was end-of-life care discussed	1.5	21.5	39.2	33.8	3.8
Only with family, and excluded the patient	5.4	21.5	37.7	31.5	3.8
How often was information given to patients or family members changed	3.8	26.9	39.2	27.7	2.3
How often did health care professionals decide on end-of-life care without including the patients or family members	44.6	46.2	6.9	1.5	0.8

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IPF, idiopathic pulmonary fibrosis

Data are expressed as percentages.

Table 3. Barriers to palliative care of patients with IPF.

Few established treatment and difficulty in predicting prognosis ($\alpha = 0.80$)	Not	Minimal	Moderate	Large	Huge
Difficult to predict the prognosis or disease progression ^a	0.8	3.8	28.5	44.6	22.3
Few established treatments to improve survival ^a	2.3	13.1	18.5	39.2	26.9
Few established treatments to relieve the symptoms ^a	0.8	4.6	23.1	43.1	28.5
Doctors involved in outpatient care and inpatient care are different	13.1	30.8	28.5	18.5	9.2
Discrepancies in understanding and care goals among patients, family and medical staff ($\alpha = 0.96$)	Not	Minimal	Moderate	Large	Huge
Disagreements between family and doctors about care goals	2.3	13.8	25.4	37.7	21.5
Disagreements between family and patient about care goals ^a	0.8	14.6	24.6	40.0	20.0
There is no nearby clinic that can provide palliative care at home	3.1	12.3	32.3	37.7	14.6
Poor understanding of patient backgrounds	4.6	14.6	33.8	33.8	13.1
Patient's lack of knowledge / understanding about disease	1.5	10.0	35.4	42.3	10.8
Family's lack of knowledge / understanding about disease	1.5	10.0	33.1	42.3	13.1
Inadequate communication about goal of care ($\alpha = 0.91$)	Not	Minimal	Moderate	Large	Huge
Inadequate communication between physician and patient/families about appropriate goals of care	5.4	14.6	29.2	33.1	17.7
Inadequate communication within medical staff about appropriate goals of care	8.5	19.2	30.0	30.8	11.5
Unrealistic physician expectations about efficacy of treatment of IPF	16.2	21.5	30.0	25.4	6.9
Physician reluctance to use opiates or sedatives for symptom management	11.5	29.2	24.6	26.2	8.5
Unrealistic expectations by patients ($\alpha = 0.82$)	Not	Minimal	Moderate	Large	Huge
Unrealistic patient expectations about prognosis or likelihood of survival	3.8	33.8	33.8	40.0	10.8
Unrealistic patient expectations about efficacy of treatment of IPF	3.8	32.3	32.3	37.7	10.0
Unwillingness of patients to plan end-of-life care	1.5	35.4	35.4	39.2	12.3
Unrealistic expectations by the family ($\alpha = 0.98$)	Not	Minimal	Moderate	Large	Huge
Unrealistic family expectations about prognosis or likelihood of survival	1.5	13.8	26.2	44.6	13.8
Unrealistic family expectations about efficacy of treatment of IPF	1.5	13.1	27	45.4	12.3
Lack of palliative care training of physicians ($\alpha = 0.88$)	Not	Minimal	Moderate	Large	Huge
Insufficient physician training in symptom management of patients with IPF	2.3	14.6	36.2	37.7	9.2
Insufficient physician training in communication about end-of-life care issues	3.1	21.5	35.4	30.8	9.2

460 Data are expressed as percentages.

461 ^aBarriers considered significant.

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463 **Figure Legends**

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465 **Figure 1. Differences in palliative care between patients with IPF and lung cancer**

466 Bars show the mean with 95% confidence intervals.

467 Abbreviation: IPF, idiopathic pulmonary fibrosis

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469 **Figure 2. Ideal and actual timing of end-of-life communication in patients with IPF**

470 Abbreviations: IPF, idiopathic pulmonary fibrosis

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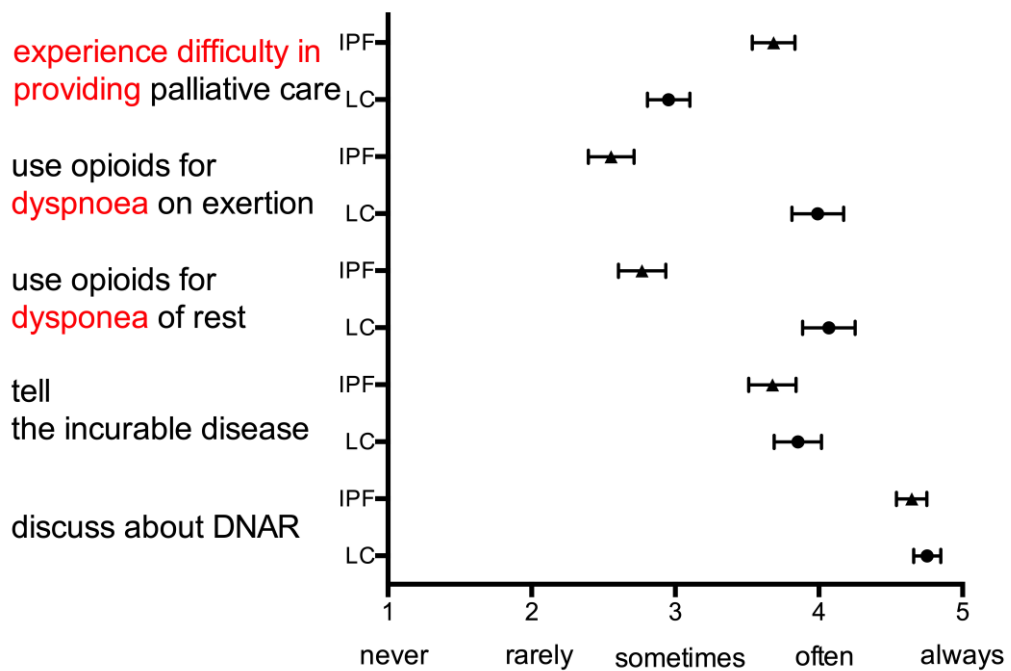
472 **Figure 3. Nominal logistic regression analysis after adjusting for respondent background**

473 The odds ratio (OR) with 95% confidence intervals is shown in each domain.

474 ‘Few established treatment and difficulty in predicting prognosis’ (OR 2.0; $p = 0.04$), ‘discrepancies in
475 understanding and care goals among patients, family and medical staff’ (OR 2.2; p value = 0.03) and
476 ‘inadequate communication about goal of care’ (OR 2.3; $p = 0.003$) were significantly associated with
477 the difficulty in providing palliative care for patients with IPF.

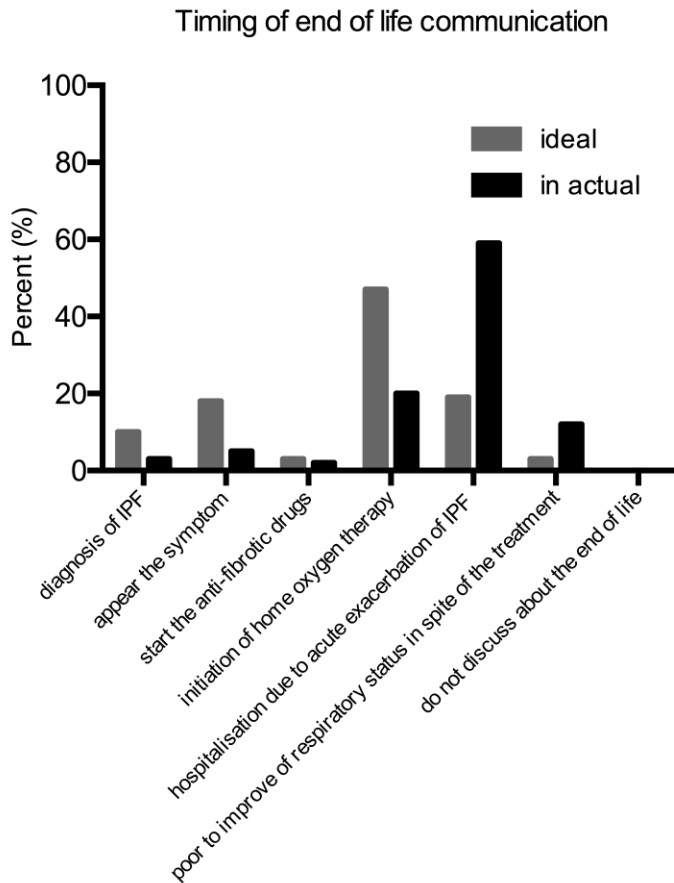
478 Abbreviations: IPF, idiopathic pulmonary fibrosis; OR, Odds ratio

Figure.1



本文のfigure1の解説に沿って赤文字部分を修正してあります。

Figure.2



本文のfigure2の解説に沿って修正してあります。

Diagnosis → diagnosis of IPF

Start the home-oxygen therapy → initiation of home oxygen therapy

Need hospitalization because of acute exacerbation of IPF

→hospitalization due to acute exacerbation of IPF

Figure.3

Nominal logistic regression analysis
adjusted with participant's age, facility type, number of ILD patients died in the last year

