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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**

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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, nasogastric 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**

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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**

Patient was free from pain.  
Patient was free from physical distress.  
Patient was free from emotional distress.

**III. Maintaining hope and pleasure**

Patient lived positively.  
Patient had some pleasure in daily life.  
Patient lived in hope.

**V. Not being a burden to others**

Patient was not being a burden to others (\*).  
Patient was not being a burden to family members (\*).  
Patient had no financial worries (\*).

**VII. Independence**

Patient was independent in moving or waking up.  
Patient was independent in daily activities.  
Patient was not troubled with excretion.

**IX. Being respected as an individual**

Patient was not treated as an object or a child.  
Patient was respected for his or her values.  
Patient was valued as a person.

**XI. Receiving enough treatment**

Patient received enough treatment.  
Patient believed that all available treatments were used.  
Patient fought against disease until the last moment.

**XIII. Preparation for death**

Patient met people whom he or she wanted to see.  
Patient felt thankful to people.  
Patient was able to say what he or she wanted to dear people.

**XV. Unawareness of death**

Patient died without awareness that he or she was dying.  
Patient lived as usual without thinking about death.  
Patient was not informed of bad news.

**XVII. Feeling that one's life is worth living**

Patient felt that he or she could contribute to others.  
Patient felt that his or her life is worth living.  
Patient maintained his or her role in family or occupation.

**II. Dying in a favourite place**

Patient was able to stay at his or her favorite place.  
Patient was able to die at his or her favorite place.  
The place of death met the preference of the patient.

**IV. Good relationship with medical staff**

Patient trusted the physician.  
Patient had a professional nurse with whom he or she felt comfortable.  
Patient had people who listened.

**VI. Good relationship with family**

Patient had family support.  
Patient spent enough time with his or her family.  
Patient had family to whom he or she could express feelings.

**VIII. Environmental comfort**

Patient lived in quiet circumstances.  
Patient lived in calm circumstances.  
Patient was not troubled by other people.

**X. Life completion**

Patient had no regrets.  
Patient felt that his or her life was completed.  
Patient felt that his or her life was fulfilling.

**XII. Natural death**

Patient was not connected to medical instruments or tubes.  
Patient did not receive excessive treatment.  
Patient died a natural death.

**XIV. Control over the future**

Patient knew how long he or she was expected to live.  
Patient knew what to expect about his or her condition in the future.  
Patient participated in decisions about treatment strategy.

**XVI. Pride and beauty**

Patient felt burden of a change in his or her appearance (\*).  
Patient felt burden of receiving pity from others (\*).  
Patient felt burden of exposing his or her physical and mental weakness to family (\*).

**XVIII. Religious and spiritual comfort**

Patient was supported by religion.  
Patient had faith.  
Patient felt that he or she was protected by a higher power.

(\*) Inverse items.

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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.



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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.

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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.

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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.