중증말기호흡기질환 정의와 치료

Definition and Timing of Palliative and End-of-Life Care

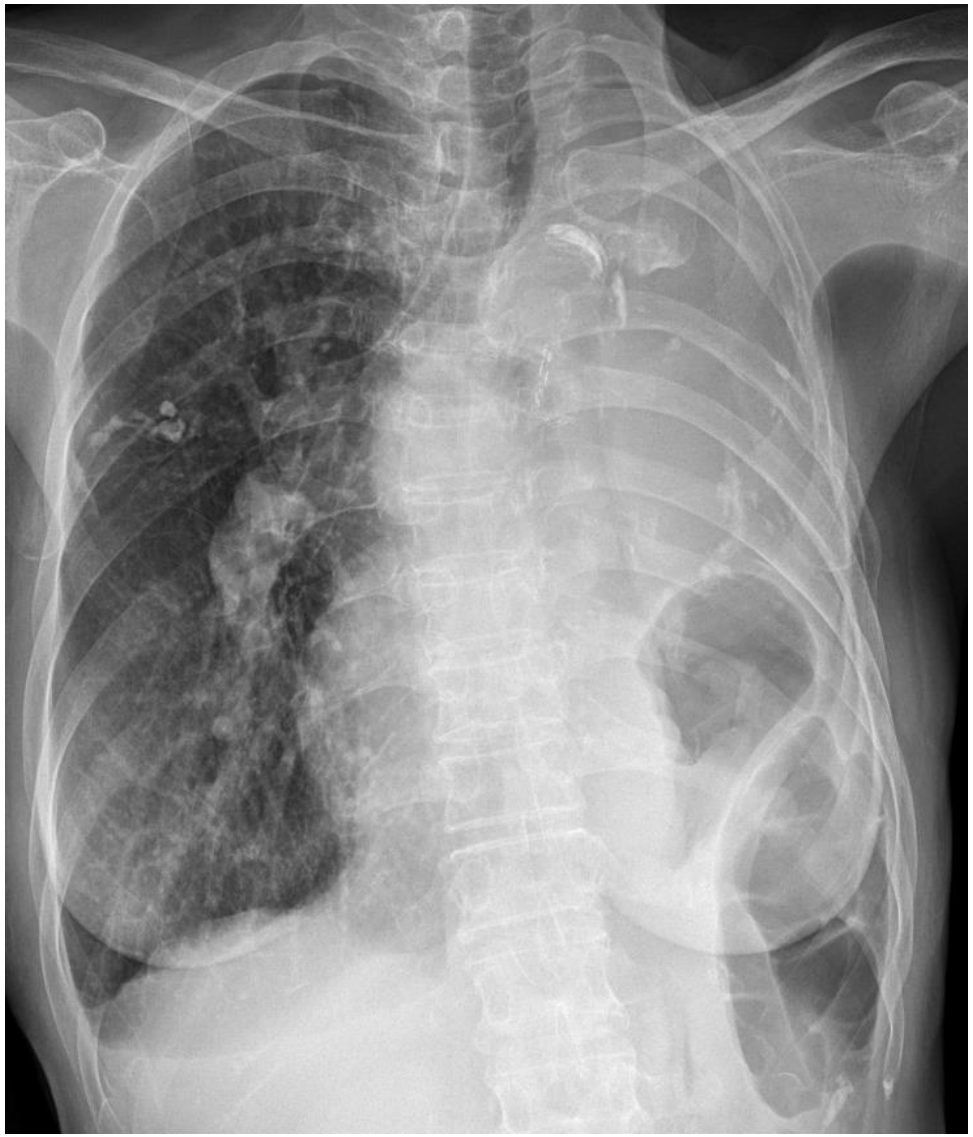
Inje University Busan Paik Hospital
Division of Pulmonary and Critical Care Medicine
Lee Hongyeul



Case. F/67 Dyspnea

- TB destroyed lung 로 호흡기 내과에서 재택 산소 및 비침습성 인공호흡기 사용 중인 자로, 내원 3일전부터 호흡곤란이 심해지고 전신 쇠약감이 심해지면서 산소를 사용 중에도 산소포화도가 감소되어 내원함.

Blood gas - pH	▼7.220	
Blood gas - pCO2	▲116	mmHg
Blood gas - pO2	▼68.4	mmHg
Blood gas - Base excess,ECF	▲19.8	mmol/L
Blood gas - Base excess	▲16.0	mmol/L
Blood gas - Bicarbonate,std	▲39.9	mmol/L
Blood gas - Bicarbonate,act	▲47.5	mmol/L
Blood gas - Total CO2	▲46.1	mmol/L
Blood gas - O2 saturation	90.7	%
Blood gas - O2 content	▼5.7	mmol/L
Blood gas - Anion gap. K	7.5	mmol/L
Ionized Ca, Blood gas	1.20	mmol/L
Ionized Ca,normalized	1.08	mmol/L
Lactic acid, Blood gas	▼0.3	mmol/L



Case. F/67 Dyspnea

- TB destroyed lung 로 호흡기 내과에서 재택 산소 및 비침습성 인공호흡기 사용 중인 자로, 내원 3일전부터 호흡곤란이 심해지고 전신 쇠약감이 심해지면서 산소를 사용 중에도 산소포화도가 감소되어 내원함.

		PRED	PRE-RX_BEST	PRE-RX_%PRED
FVC	Liters	2.94	0.73	25
FEV1	Liters	2.31	0.41	18
FEV1/FVC	%	77	56	
FEF25-75%	L/sec	2.25	0.21	9
PEF	L/sec	5.28	1.50	28
PIF	L/sec		0.74	
FET100%	Sec		5.11	
MVV	L/min	86		

* Total distance walked in 6 minutes - 120(m)
  Number of laps 2 (*60 meters) + Final partial lap 0 (meters)

* Minimal SpO_2 during exercise - 86(%)

**Insihgt(+) 본인/남편:폐질환으로 인한 심장기능장애(우심부전)
: 예후가 불량하며 폐이식이외에 치료 방법은 없으나 치료 예후는 불량함. (양산부산대 교수님과 상담)
** Saturation(RA)84%-HomeO2 사용시2L: 96%
NIV (2019.5) > PSV(2025.5): IPEP18-EPAP4 RR 16 : MV5L/m 이상을 목표로.
Home O2(2020.3.18) 0.5 / 1.5(NIV시) (매년 2.25-)

검사명 (*:중간보고)	결과	단위
Blood gas - Hb	10.0	g/dL
Blood gas - Hct	29	%
Blood gas - pH	7.358	
Blood gas - pCO2	70.9	mmHg
Blood gas - pO2	29.3	mmHg
Blood gas - Base excess,ECF	13.5	mmol/L
Blood gas - Base excess	11.4	mmol/L
Blood gas - Bicarbonate,std	34.0	mmol/L
Blood gas - Bicarbonate,act	39.0	mmol/L
Blood gas - Total CO2	41.2	mmol/L
Blood gas - O2 saturation	43.3	%
Blood gas - O2 content	2.7	mmol/L
Blood gas - Anion gap. K	13.3	mmol/L
Ionized Ca, Blood gas	1.14	mmol/L
Ionized Ca,normalized	1.12	mmol/L
Lactic acid, Blood gas	1.13	mmol/L

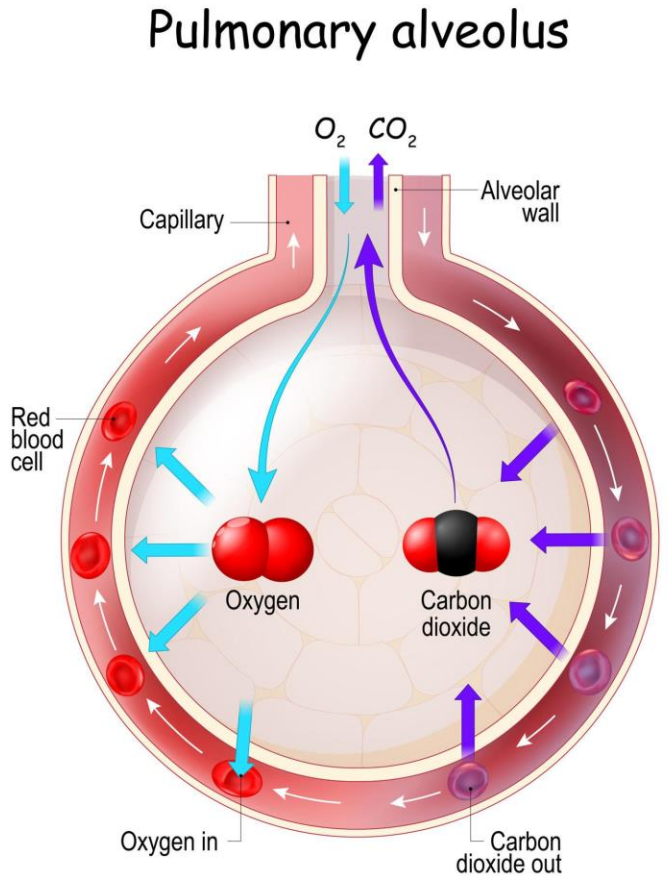
Index – Estabilished Concept

- Chronic respiratory failure
- 중증말기 호흡기질환
- Palliative treatment
- Advanced care plan

Respiratory Function

- **Oxygenation**
- : The process of transferring oxygen (O_2) from the alveoli into the pulmonary capillary blood.

- **Ventilation**
- : The process of eliminating carbon dioxide (CO_2) produced by cellular metabolism from the body through alveolar ventilation.



Jpn Soc Respir Care Rehabil. 2023

Criteria for pulmonary and respiratory failure in COPD patients – a theoretical study based on clinical data

Respiration. 1982;43(6):436-43. doi: 10.1159/000194515.

Current Criteria of Chronic Respiratory Failure

The Respiratory Failure Research Group supported by the Japanese Ministry of Health and Welfare started clinical research and conducted a nation-wide survey in 1978. In 1983, the group proposed a criterion that chronic respiratory failure is defined as arterial blood oxygen tension (PaO_2) of below 60 mmHg during room air breathing or the clinical state corresponding to this level. Additionally, type I failure is defined as arterial carbon dioxide tension ($PaCO_2$) of below 45 mmHg and type II failure, $PaCO_2$ over 45 mmHg. Several reports on patients with chronic respiratory failure (mostly due to COPD) suggest that a PaO_2 of 60 mmHg is a critical level of deteriorated pulmonary as well as circulatory abnormalities (2). This level

Chronic Respiratory Failure
- **PaO_2 <60 mmHg**
- **$PaCO_2$ >45 mmHg**
- **1 Months**

Respiration. 1982;43(6):436-43.
Jpn Soc Respir Care Rehabil. 2023

Respiratory System

① Chemical stimulus
↑ $PaCO_2$, ↓ pH, ↓ PaO_2

↓

② Central chemoreceptor
Senses ↑ CO_2/H^+ in CSF

② Peripheral chemoreceptor
Senses ↓ O_2, ↑ CO_2/H^+ in carotid and aortic bodies

↓

③ Respiratory center in the brain
Integrates input from chemoreceptors and regulates the pattern and depth of breathing

↓

④ Respiratory and motor neurons
Phrenic nerve (C3–C5), intercostal nerves (T1–T11)

↓

⑤ Respiratory muscles and chest wall
Contraction of respiratory muscles → ↑ thoracic volume → ↓ intrathoracic pressure → airflow

↓

⑥ Alveolar ventilation and gas exchange
O_2 diffuses into blood, CO_2 diffuses into alveoli

Primary central hypoventilation syndrome (CCHS), congenital respiratory center dysfunction

Brain injury, brain tumor, central sleep apnea

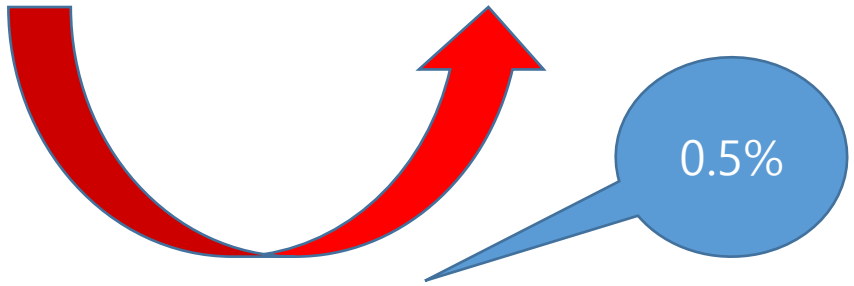
Stroke, head trauma, ALS, Guillain–Barré syndrome
Brainstem tumor
Sedative or analgesic drug effects

Neuromuscular disorders, spinal cord injury, phrenic nerve paralysis
Muscular dystrophy, severe obesity, chest wall deformities
COPD, asthma, pulmonary edema, chest wall disease

ILD, pulmonary fibrosis, pleural effusion, pneumothorax
Pulmonary edema, pneumonia

Current Hospice Utility in Korea

연도	암			대상질환(암 및 비암성)		
	사망자 수[1]	신규 환자 수[2]	이용률[3]	사망자 수[1]	신규 환자 수[2]	이용률[3]
2008	68,912	5,046	7.3	68,912	5,046	7.3
2009	69,780	6,365	9.1	69,780	6,365	9.1
2010	72,046	7,654	10.6	72,046	7,654	10.6
2021	82,688	19,185	23.2	89,460	19,228	21.5
2022	83,378	20,198	24.2	96,619	20,266	21.0
2023	85,271	22,323	26.2	99,421	22,394	22.5



사망자: +14,140명
신규 환자수: +71명

암종	2022년		2023년		2024년	
	빈도	백분율	빈도	백분율	빈도	백분율
만성 폐쇄성 호흡기질환	19	27.9	16	22.5	37	33.9
만성 폐쇄성 호흡기질환, 만성호흡부전	12	17.6	3	4.2	15	13.8
만성 간경화	27	39.8	30	42.3	25	22.9
만성호흡부전	9	13.2	22	31.0	32	29.4
후천성 면역결핍증	1	1.5	0	0.0	0	0.0
계	68	100.0	71	100.0	109	100.0

2025 국가호스피스 완화의료 연례보고서

호스피스·완화의료 및 임종과정에 있는 환자의 연명의료결정에 관한 법률 호스피스·완화의료 및 임종과정에 있는 환자의 연명의료결정에 관한 법률 시행규칙

"호스피스·완화의료"(이하 "호스피스"라 한다)란 다음 각 목의 어느 하나에 해당하는 질환으로 말기환자로 진단을 받은 환자 또는 임종과정에 있는 환자(이하 "호스피스대상환자"라 한다)와 그 가족에게 통증과 증상의 완화 등을 포함한 신체적, 심리사회적, 영적 영역에 대한 종합적인 평가와 치료를 목적으로 하는 의료를 말한다.

가. 암

나. 후천성면역결핍증

다. 만성 폐쇄성 호흡기질환

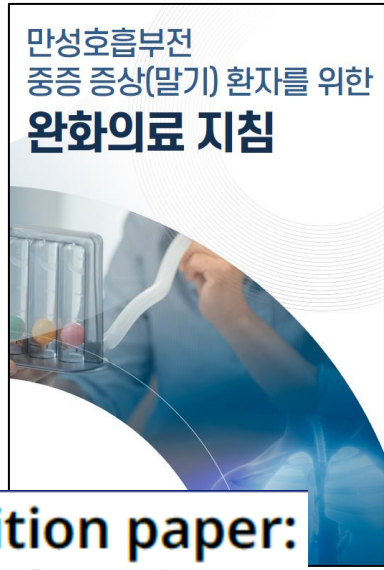
라. 만성 간경화

마. 그 밖에 보건복지부령으로 정하는 질환

질 환	질병코드 KCD	진단명
만성호흡부전	J42	상세불명의 만성 기관지염
	J45	천식
	J46	천식지속상태
	J47	기관지확장증
	J60	탄광부진폐증
	J61	석면 및 기타 광섬유에 의한 진폐증
	J62	실리카를 함유한 먼지에 의한 진폐증
	J64	상세불명의 진폐증
	J65	결핵과 연관된 진폐증
	J80	성인호흡곤란증후군
	J84	기타 간질성 폐질환
	J96	달리 분류되지 않은 호흡부전
	J98	기타 호흡장애

Definition of end stage of chronic lung disease

- 중증 비암성 만성 폐질환(Advanced Non-malignant Chronic lung disease)
- 중증 비암성 만성 호흡기질환 (Advanced Non-malignant Chronic pulmonary disease)
- 만성호흡부전 중증 증상(말기) 환자
- 만성 진행성 비암성 폐질환 (Chronic Progressive Non-malignant lung disease)



만성 비암성 폐질환 환자를 위한 완화의료 국외 참고자료

보건복지부 Ministry of Health and Welfare

중앙호스피스센터 National Hospice Center



Danish respiratory society position paper: palliative care in patients with chronic progressive non-malignant lung diseases

European Clinical Respiratory Journal

ISSN: 2001-8525 (Online) Journal homepage: www.tandfonline.com/journals/zecr2(

Definition of Advanced(Serious) illness

- "Serious illness" is defined as a condition associated with:
  1) a **high risk of mortality**,
  2) significant **symptom burden and/or caregiver distress**.
  3) substantial impairment in **quality of life** and **daily functioning**

J Palliat Med 2014; 17: 985.

Table 1: Definitions of advanced COPD

Items	Criteria
Definition of end-stage pulmonary disease (life expectancy of 6 months or less) by the US National Hospice and Palliative Care Organization	
Severe chronic lung disease	
Disabling dyspnea	Dyspnea at rest, poorly or unresponsive to bronchodilators, resulting in decreased functional capacity (e.g., bed-to-chair existence), fatigue, and cough. Objective evidence: FEV_1 < 30% pred after bronchodilator (not necessary to obtain)
Disease progression	Increasing visits to the emergency department or hospitalizations for pulmonary infections and/or respiratory failure or increasing clinician home visits before initial certification. Objective evidence: serial decrease of FEV_1 > 40 ml/year (not necessary to obtain)
Hypoxemia at rest on room air	PO_2 ≤55 mmHg or oxygen saturation ≤88% on supplemental oxygen determined either by arterial blood gases or oxygen saturation monitors or hypercapnia, as evidenced by PCO_2 ≥50 mmHg
Right heart failure	Secondary to pulmonary disease (cor pulmonale) (e.g., not secondary to left heart disease or valvulopathy)
Unintentional progressive weight loss	>10% of body weight over the preceding 6 months
Resting tachycardia	>100/min
Definition of end-stage COPD by clinical features	
Airflow limitation	Very severe (FEV_1 <30% pred)
Performance status	Severely limited and declining
Other criteria (at least one)	Advanced age; Presence of multiple comorbidities; Severe systemic manifestations/complications of COPD (e.g. chronic respiratory failure, body composition alterations, peripheral muscle dysfunction, respiratory muscle dysfunction, osteoporosis, pulmonary hypertension, cardiac impairment, fluid retention/edema)
Group D patients defined by GOLD	
Characteristic	High risk, more symptoms (compared with group A, B and C patients)
Spirometric classification	GOLD 3 or 4 (Severe or Very Severe airflow limitation)
Exacerbations per year	≥2
mMRC or CAT	mMRC grade ≥ 2 or CAT score ≥ 10

FEV_1: Forced expiratory volume in 1 s; COPD: Chronic obstructive pulmonary disease; GOLD: Global Initiative for Chronic Obstructive Lung Disease; mMRC: Modified British Medical Research Council questionnaire; CAT: Chronic Obstructive Pulmonary Disease Assessment Test.

The National Hospice Organization. Hosp J 1996;11:47-63.

Poor prognostic predictors in COPD

Characteristics	BODE Index	ADO Index	DOSE Index
Year introduced	2004	2009	2009
Primary purpose	Mortality prediction	Mortality prediction	Disease burden and healthcare utilization
Score range	0–10	0–10 (original); 0–14 (updated)	0–8
Age	No	Yes	No
BMI	Yes	No	No
FEV_1	Yes	Yes	Yes
Dyspnea (mMRC)	Yes	Yes	Yes
6-minute walk distance	Yes	No	No
Exacerbation frequency	No	No	Yes
Smoking status	No	No	Yes

Celli et al., 2004 – BODE index (NEJM)
Puhan et al., 2009 – ADO index (Thorax)
Jones et al., 2011 – DOSE index (Thorax)

Practical synthesis used in many studies

- **Advanced airway disease with**

  - Severe irreversible airflow limitation
  - Chronic respiratory failure (LTOT ± NIV)

  Physiological impairment

  - Refractory dyspnea and functional dependence

  Symptomes
  Funtional impact

  - Recurrent hospitalizations or ICU admissions
  - Progressive decline despite maximal guideline-based therapy

  Disease . Course

- This constellation with **high 6–12-month mortality**

호스피스·완화의료 및 임종과정에 있는 환자의 연명의료결정에 관한 법률 (약칭 : 연명의료결정법)

[시행 2018.2.4.] [법률 제14013호, 2016.2.3., 제정]

보건복지부 (생명윤리정책과 - 연명의료결정) 044 - 202 - 2942

보건복지부 (질병정책과 - 호스피스 완화의료) 044 - 202 - 2517

"말기환자(末期患者)"란 적극적인 치료에도 불구하고 근원적인 회복의 가능성이 없고 점차 증상이 악화되어 보건복지부령으로 정하는 절차와 기준에 따라 담당의사와 해당 분야의 전문의 1명으로부터 수개월 이내에 사망할 것으로 예상되는 진단을 받은 환자를 말한다.

가. 암

나. 후천성면역결핍증

다. 만성 폐쇄성 호흡기질환

라. 만성 간경화

마. 그 밖에 보건복지부령으로 정하는 질환



가. 삭제 <2018. 3. 27.>

나. 삭제 <2018. 3. 27.>

다. 삭제 <2018. 3. 27.>

라. 삭제 <2018. 3. 27.>

마. 삭제 <2018. 3. 27.>

연명의료결정제도 안내

2024.



보건복지부

국가생명윤리정책원
국립연명의료관리기관

말기환자의 의미와 진단기준

- "말기환자(末期患者)"란 적극적인 치료에도 불구하고 근원적인 회복의 가능성이 없고 점차 증상이 악화되어 담당의사와 해당 분야의 전문의 1명으로부터 수개월 이내에 사망할 것으로 예상되는 진단을 받은 환자를 말합니다(「호스피스·완화의료 및 임종과정에 있는 환자의 연명의료결정에 관한 법률」 제2조제3호).
- 담당의사와 해당 분야 전문의 1명이 말기환자 여부를 진단하는 경우에는 다음의 기준을 종합적으로 고려해야 합니다(「호스피스·완화의료 및 임종과정에 있는 환자의 연명의료결정에 관한 법률 시행규칙」 제2조).

1. 임상적 증상
2. 다른 질병 또는 질환의 존재 여부
3. 약물 투여 또는 시술 등에 따른 개선 정도
4. 종전의 진료 경과
5. 다른 진료 방법의 가능 여부
6. 그 밖에 1.부터 5.까지에 준하는 것으로서 말기환자의 진단을 위하여 보건복지부장관이 특히 필요하다고 인정하는 기준

연명의료결정제도 안내 보건복지부, 2024, 34쪽

말기와 임종과정에 대한 정의 및 의학적 판단지침

J Korean Med Assoc 2018 August; 61(8):509-521

1. 암
2. 후천성면역결핍증
3. 호흡기질환
4. 간질환(만성간경화 포함)
5. 만성심장질환
6. 뇌혈관질환
   (1) 급성기 뇌졸증
   (2) 만성기 뇌졸증
7. 신장질환
8. 신경퇴행성질환
   (1)파킨슨병 및 파킨슨 유사 증후군
   (2)근위축성측삭경화증
9. 치매
10. 말기의 일반 지표

3) 호흡기질환(만성폐쇄성폐질환, 폐섬유증, 기관지확장증 외 만성호흡기질환 포함)

다음 항목 중 1개 이상에 해당하는 경우 말기로 진단할 수 있다[13,16,37-39]. (1) 매우 심한 만성호흡기질환으로 인하여 숨이 차서 의자에 앉아 있는 것도 어려운 경우; (2) 장기간의 산소 치료를 필요로 하는 경우로서 담당의사의 판단으로 수개월 내에 사망이 예상되는 경우; (3) 호흡부전으로 장기간 인공호흡기가 필요한 경우 혹은 폐 이식이 필요하지만 금기기준에 해당하거나 환자가 이식을 거절한 경우이다.

Symptomes
Funtional impact

Physiological impairment

Physiological impairment

J Korean Med Assoc 2018 August; 61(8):509-521

만성호흡부전 중증 증상(말기) 환자의 정의

1) 완화의료를 고려하는 만성호흡부전 중증 증상(말기) 환자의 정의

회복가능성이 없는 진행된 비암성(non-malignant) 만성호흡기질환에 의해 만성호흡부전 증상이 있는 환자가 기대 여명이 수개월에서 1년 이내일 것으로 예상되는 경우 완화의료를 고려할 수 있다. 비암성 만성호흡기질환에는 만성폐쇄성폐질환(chronic obstructive pulmonary disease), 천식(bronchial asthma), 기관지확장증(bronchiectasis), 진폐증(pneumoconiosis), 사이질(간질성)폐질환(interstitial lung disease) 등 다양한 호흡기 질환이 포함된다.

2) 만성호흡부전 환자에서 완화의료를 고려하는 시기

아래 ①, ②, ③ 중에서 하나 이상에 해당되는 환자가 담당의에 의해 기대 여명이 수개월에서 1년 이내일 것으로 판단되면 완화의료를 고려할 수 있다.

① 안정 시 호흡곤란
② 폐질환으로 인해 응급실에 자주 방문하거나 자주 입원하는 경우
③ 저산소혈증으로 산소치료를 필요로 하는 환자

병명	ICD-10
기타 만성폐쇄성폐질환	J44
폐기종	J43
상세불명의 만성기관지염	J42
단순성 및 점액화농성 만성 기관지염	J41
급성인지 만성인지 명시되지 않은 기관지염	J40
천식	J45
천식지속상태	J46
기관지확장증	J47
탄광부진폐증	J60
석면 및 기타 광섬유에 의한 진폐증	J61
실리카를 함유한 먼지에 의한 진폐증	J62
상세불명의 진폐증	J64
결핵과 연관된 진폐증	J65
성인호흡곤란증후군	J80
기타 간질성 폐질환	J84
달리 분류되지 않은 호흡부전	J96
기타 호흡장애	J98

J 만성호흡부전 중증 증상(말기)환자를 위한 완화의료 지침



Post-bronchodilator FEV1/FVC < 0.7

GRADE	FEV1 (% predicted)
GOLD 1	≥ 80
GOLD 2	50-79
GOLD 3	30-49
GOLD 4	< 30

EXACERBATION HISTORY

	mMRC 0-1 CAT < 10	mMRC ≥ 2 CAT ≥ 10
≥ 2 moderate exacerbations or ≥ 1 leading to hospitalization	E	
0 or 1 moderate exacerbations (not leading to hospitalization)	A	B

SYMPTOMS

Chronic Progressive Non-malignant lung disease

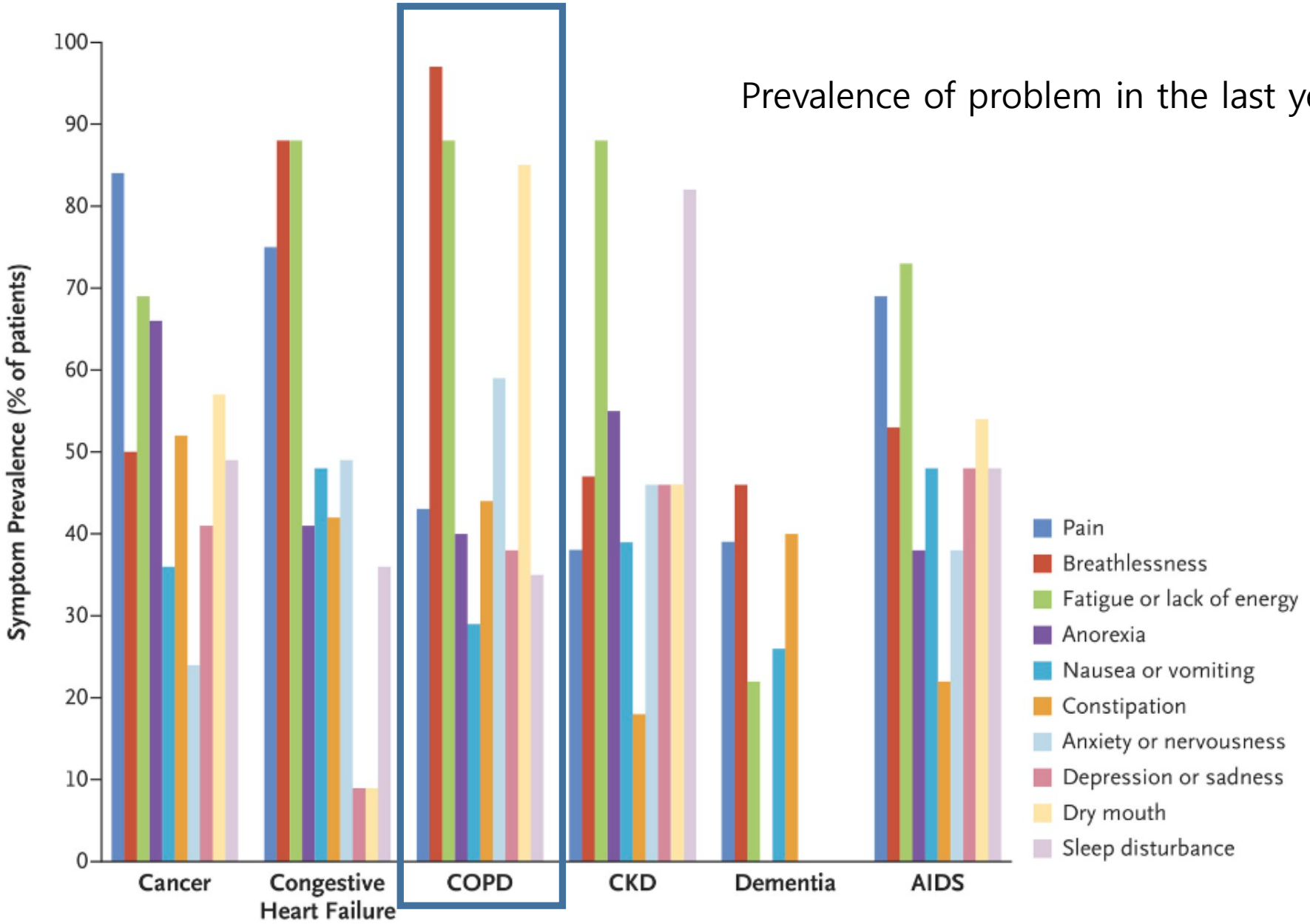
- "Serious illness" is defined as a condition associated with:
  1) a **high risk of mortality** = **Criteria of diagnosis**
  2) significant **symptom burden and/or caregiver distress**.
  3) substantial impairment in **quality of life** and **daily functioning**

- **Advanced airway disease with**
  - Severe irreversible airflow limitation
  - Chronic respiratory failure (LTOT ± NIV)

  - Refractory dyspnea and functional dependence

  - Recurrent hospitalizations or ICU admissions
  - Progressive decline despite maximal guideline-based therapy

Non-malignant vs Malignant lung disease



N Engl J Med 2015;373:747-55.

Symptoms of terminal patient with COPD or lung cancer

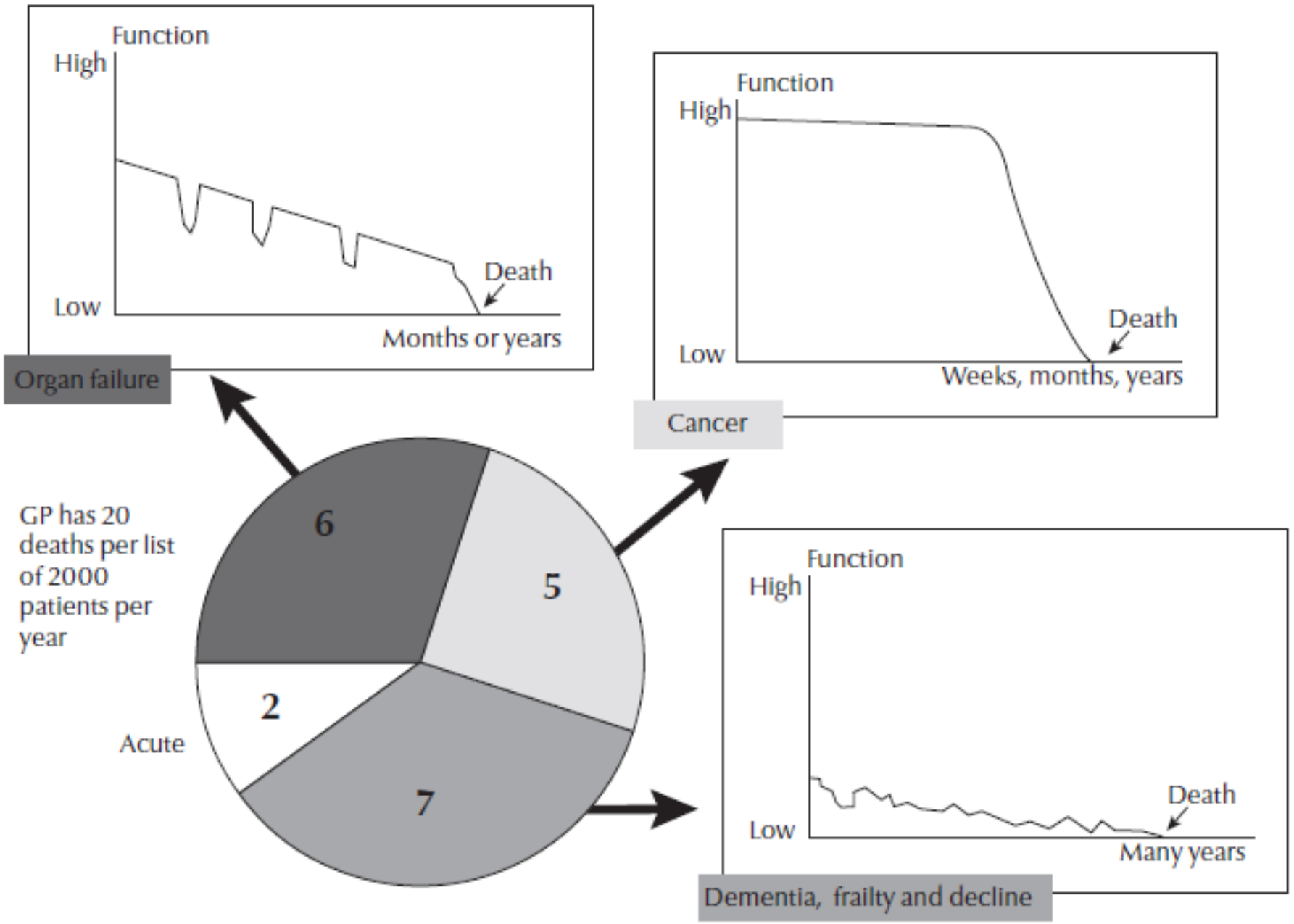
A total of 82 patients (50 COPD and 32 LC)
Cohort study
Telephon interview

Summary of Outcomes at Baseline

Outcome	COPD, *n* (%) 50 (100)	LC, *n* (%) 32 (100)	Difference (*P*-value)
Breathlessness prevalence	48 (96)	24 (75)	**0.005**
Continuous breathlessness	26 (52)	7 (22)	**0.007**
Breathlessness severity, mean (SD, range)			
Over the last 24 h	3.2 (2.3, 0–10)	1.8 (2.0, 0–7)	**0.007**
Severe scores (≥5)	16 (32)	3 (9)	**0.018**
Maximum over the last 24 h, mean (SD, range)	4.2 (2.7, 0–9)	2.1 (2.3, 0–7)	**0.001**
At the moment of interview	1.9 (1.9, 0–6)	1.0 (1.4, 0–4)	**0.018**
At rest	1.3 (1.3, 0–5)	0.8 (1.4, 0–5)	0.188
At exertion	5.3 (2.4, 0–10)	3.4 (2.6, 0–8)	**0.001**
Functional status, mean (SD, range)	68.8 (14.4, 30–90)	76.9 (15.1, 30–100)	**0.017**
<80	32 (64)	10 (31)	**0.004**
Distress, mean (SD, range)	4.6 (2.4, 0–10)	4.5 (2.3, 0–10)	0.775
Clinically meaningful scores (≥4)	37 (74)	23 (72)	0.832
Palliative care needs, mean (SD, range)	9.7 (6.9, 0–27)	10.0 (5.8, 0–22)	0.683

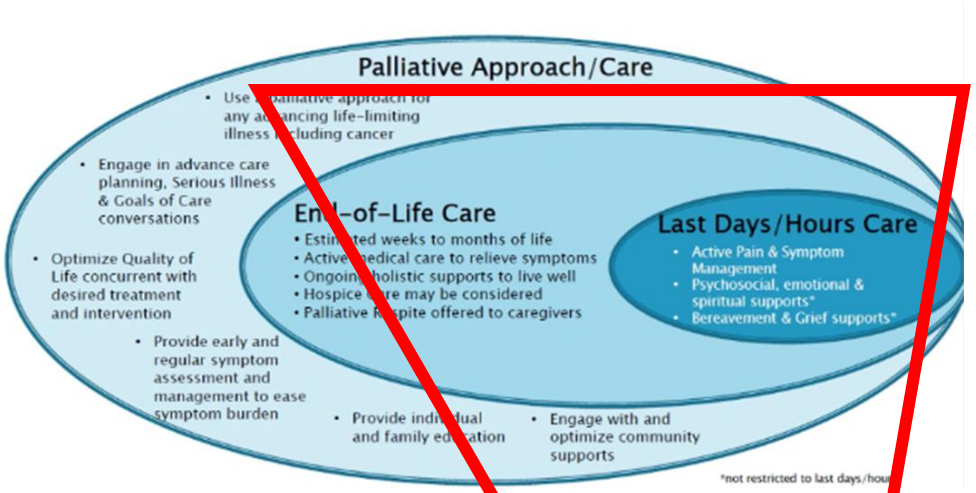
J Pain Symptom Manage. 2014 Oct;48(4)

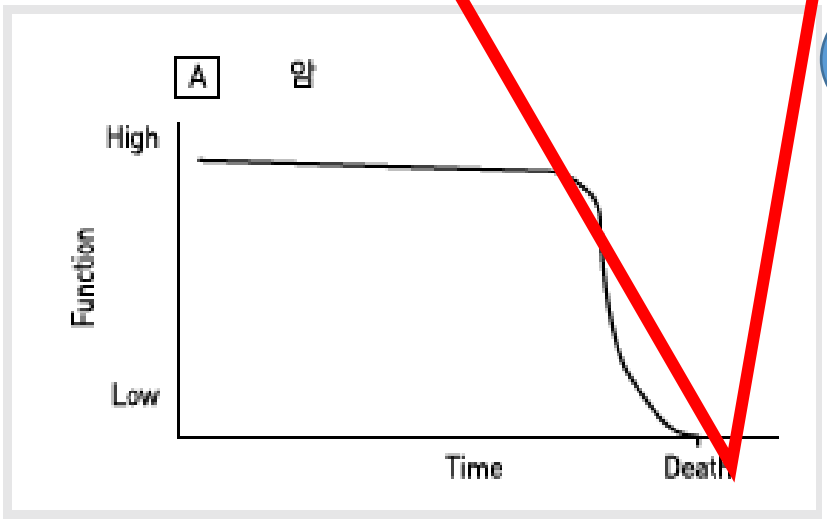
Trajectories of chronic illness



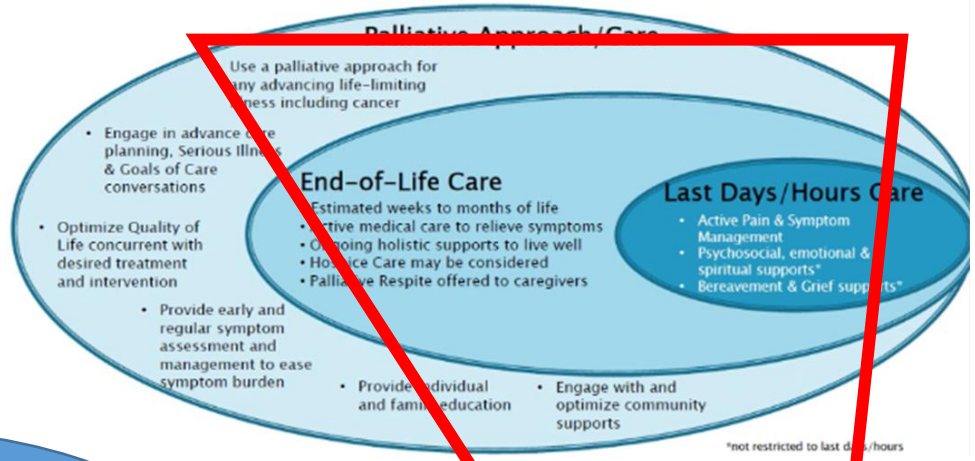
EMHJ, 2012, 18 (2): 178-183

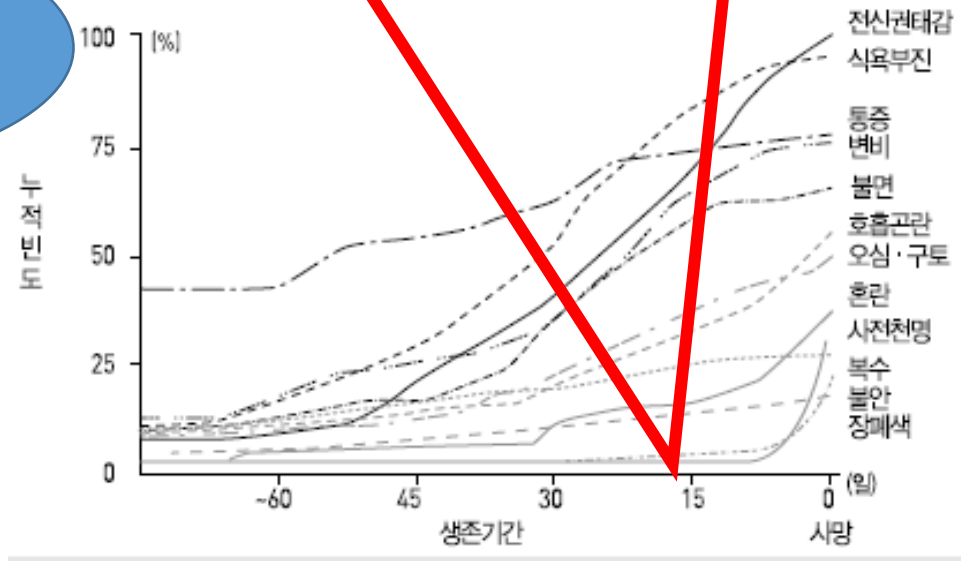
Tragedy of End stage malignant disease



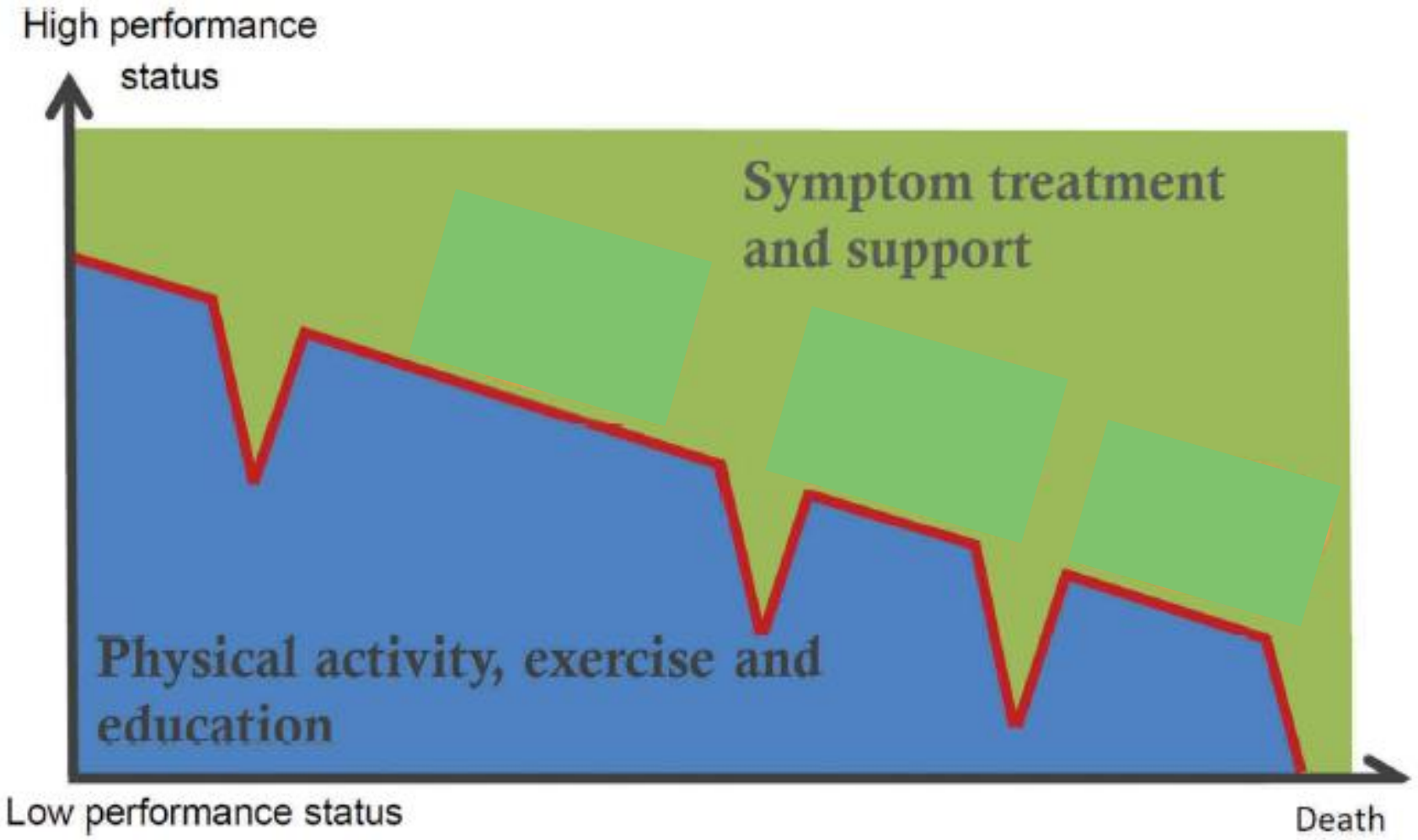


1) **high risk of mortality**,
2) **symptom burden**
3) **quality of life**



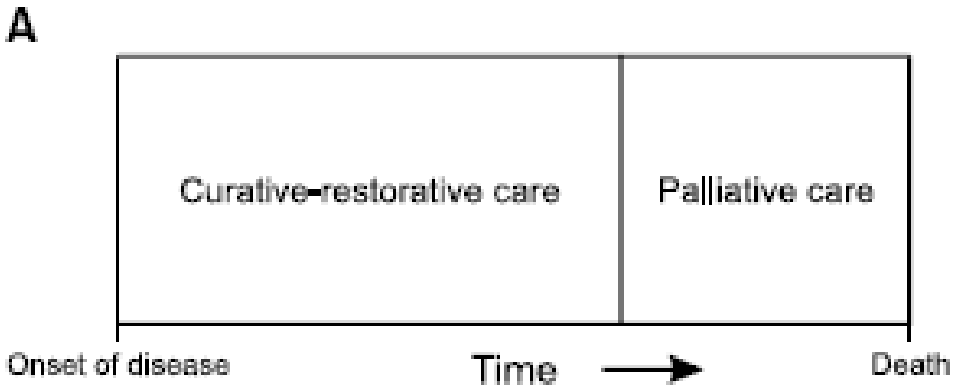


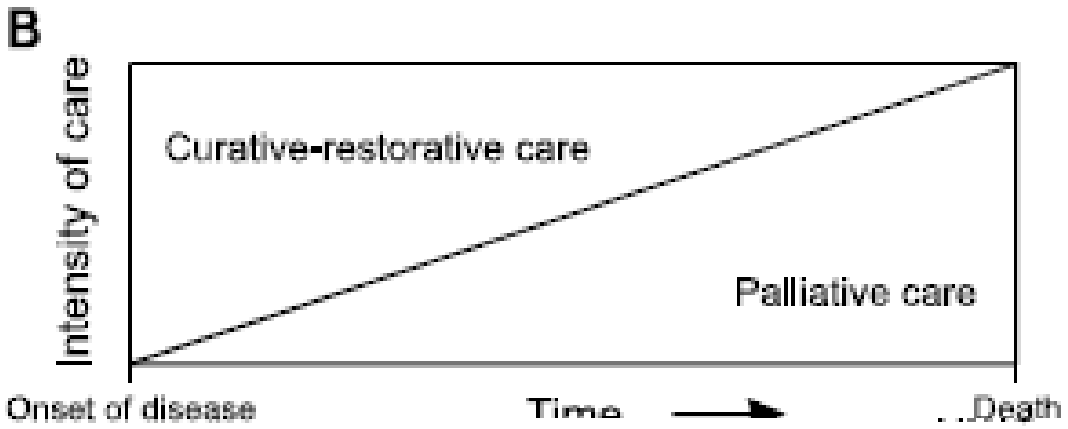
Trajecotry of chronic lung disease

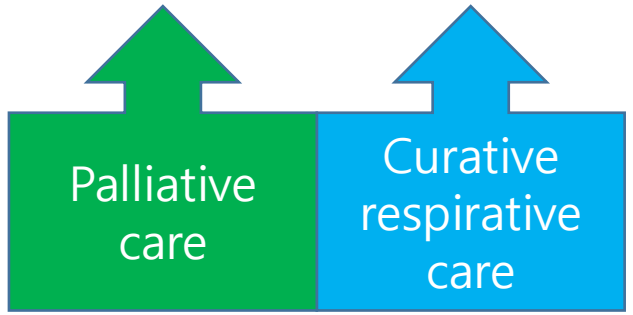


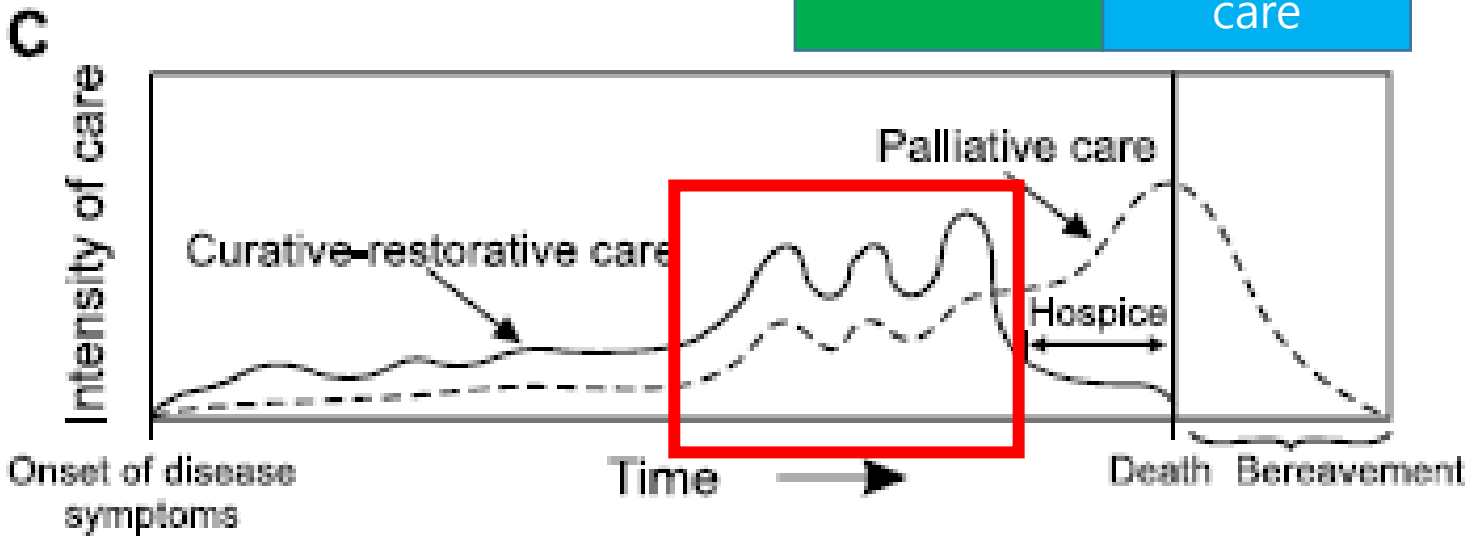
EUROPEAN CLINICAL RESPIRATORY JOURNAL 2018, VOL. 5, 1530029

An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses.



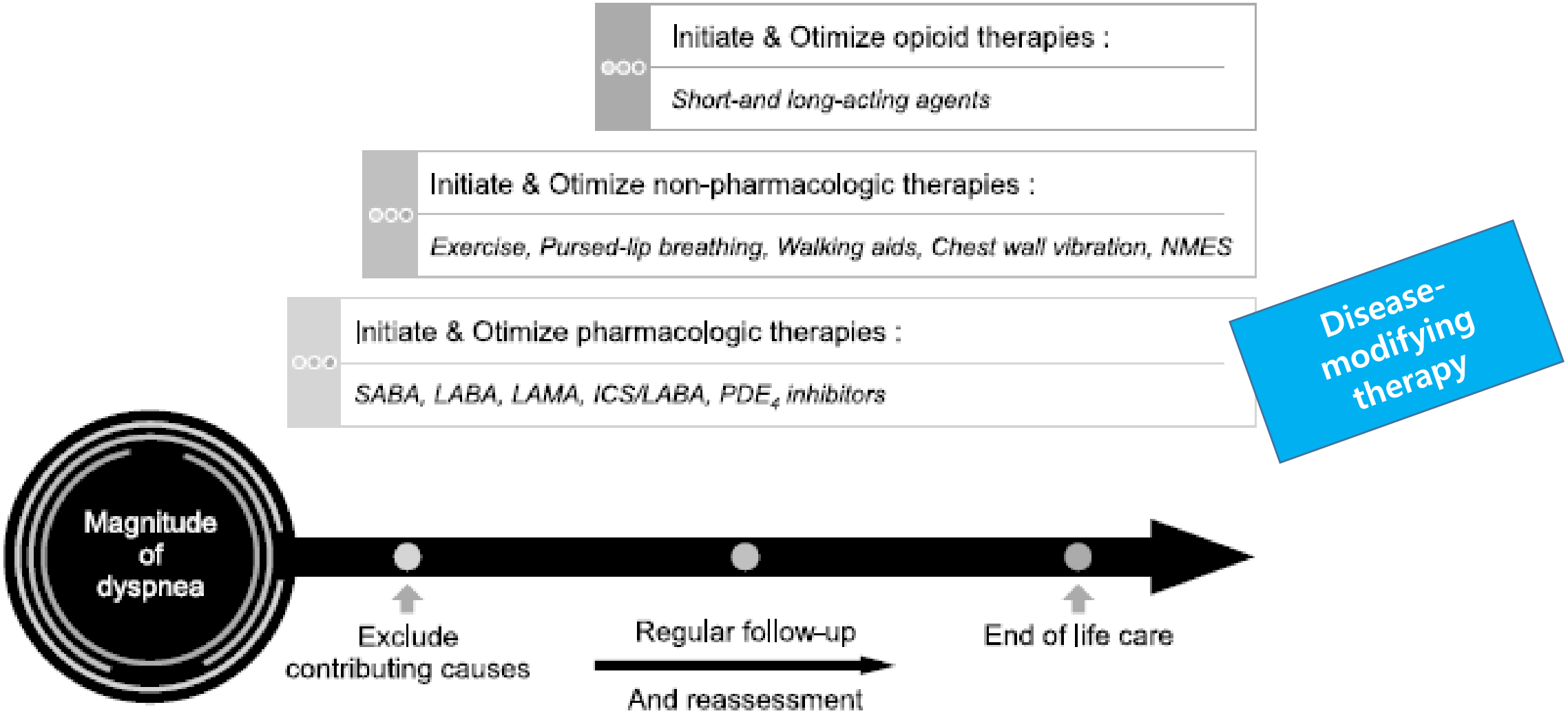






Am J Respir Crit Care Med 2008.

Comprehensive approach to the management of dyspnea in advanced COPD patients.



Hard to define
End stage in airway disease

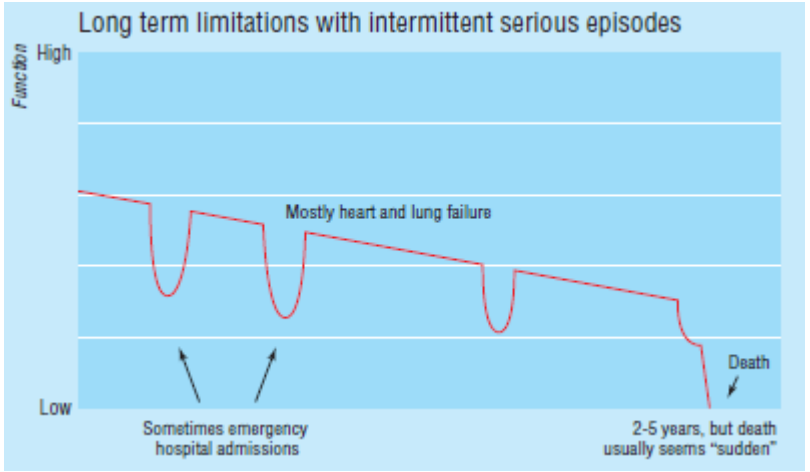
- No single standard definition
- **prolonged, fluctuating organ-failure trajectory**, unlike many cancers.

- Key challenges highlighted in the literature:

1) Prognostic uncertainty (sudden death vs slow decline)

2) Poor accuracy of physician survival prediction

3) Patients may appear “stable” shortly before death



Difficult to initiate advanced care planning

Perception of Patients with Severe COPD

A story with no beginning

I've had it forever

"How it started is anybody's guess; there is no way of knowing . . . so it has always been my belief that something happened in my younger years that started the damage." [T06.1]

Interviewer: "So when did it start?"

"Um I think I was, I mean I've always been bothered with bronchitis and things like that through my life." [L03.1]

I'll tell you about a milestone . . .

"I've had it forever"
"언제 시작됐는지는 모르겠다"
원인 설명(흡연, 직업)을 이야기함
진단 ≠ 시작

[T01.4 daughter in a joint interview with her father]

I'll link it with the story of another health problem

"I had a major op in the Infirmary in, 1985 was it? No, no, 94, 93. I had an abscess on the bowel. They thought I had cancer. I was worried." [L04.1]

I can't tell you "when" so I'll tell you "how"

Interviewer: "So when did it all start?"

"Well first of all it was with smoking. I was a smoker and just couldn't stop." [T02.1]

"See he was a smoker ..." [T05.1 wife]

"We used to put that rubber on carpets and vulcanise it . . . we didn't realise that we were inhaling all that smoke." [T05.1]

A middle that is a way of life

Part of ageing

"I fear I am getting worse (which is understandable), it's like any other illness. It's like ageing, you are getting older and that really is the illness is getting worse as well." [F06.1]

"I'm all right if I sit still. It's all just part of getting older I suppose." [T03.1]

Nothing to be done

"Oh it's certainly not very pleasant no, but that's the way it worked out, you know I tried it, it's not going to work for me whatever the reason. There's nothing can be done." [F02.1]

Exacerbations are isolated episodes

"Now I'm fine, but I had a bad time over Christmas. I got a chest infection at the beginning of December and it took me till Feb t shake it off. But no, I'm fine again now. Back to normal." [T01.4

- "It's part of getting older"
- "Nothing can be done"
- 악화는 "isolated episode"
- 회복 후: "Back to normal"

An uncertain and unlooked for end

I don't know when

Interviewer: "So, I'll come and see you again in about 6 months time . . ."

"If I am still alive in 6 months time."

Interviewer: "I hope you will be, do you think you might not be?"

"I don't know." [L04.1]

Unlooked for

"Even the doctor said that, it won't get any better. What I thought, actually I could stay in the same sort of level . . ." [F07.3]

"So. I certainly don't think I'm getting any better, but I haven't got any worse I don't think." [F10.4]

"I don't know when"
"I'm not getting better, but not worse either"

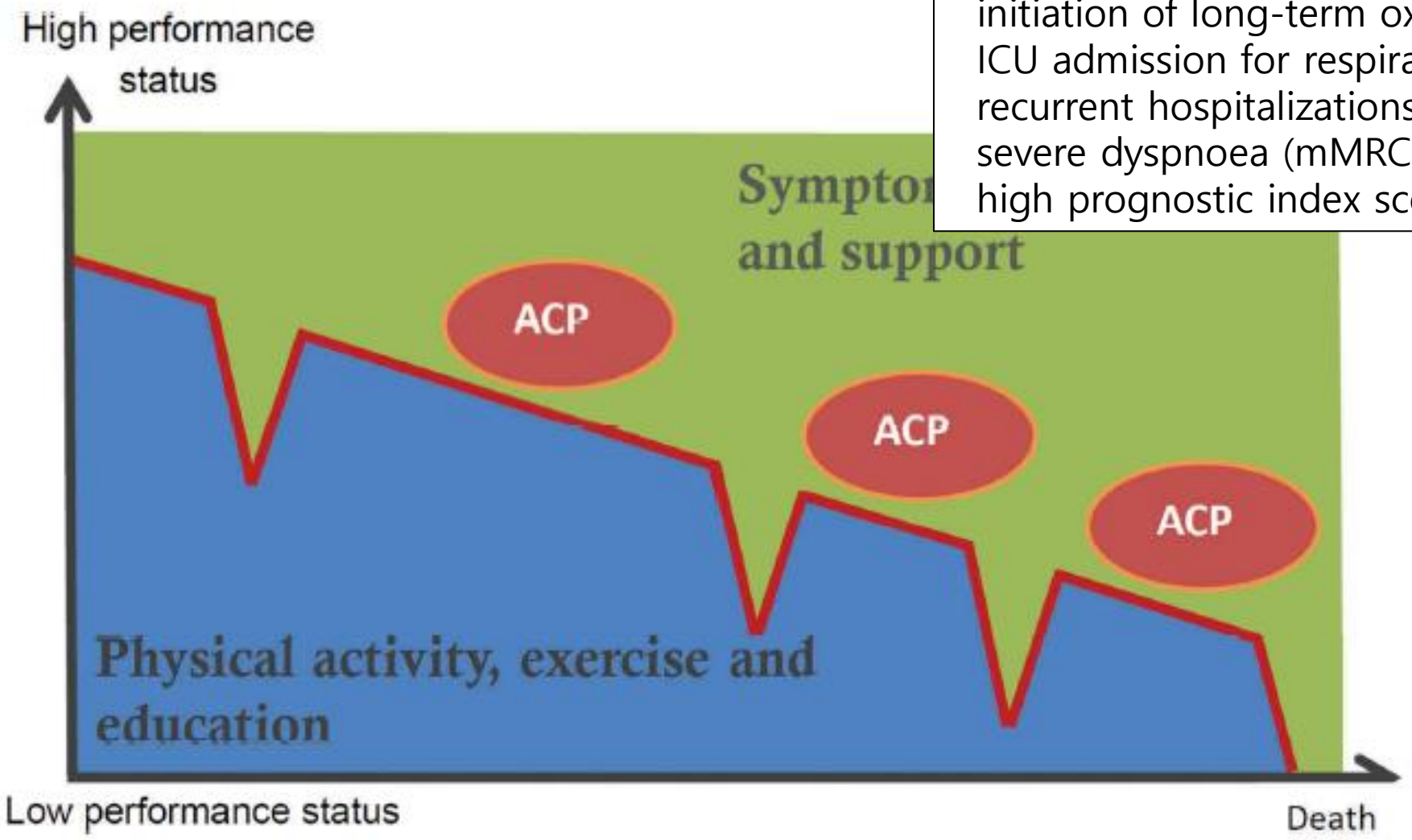
죽음은: 나이 들면 오는 일반적 인간 조건
죽음 ≠ COPD의 필연적 결과
COPD는 죽음을 *설명하지 않는 질병*

📌 암과 대비
암: "이 병으로 죽을 수 있다"
COPD: "언젠가 죽겠지"

BMJ 2011;342:d142

Clinical triggers instead of survival thresholds

Commonly proposed triggers include:
initiation of long-term oxygen therapy or home NIV,
ICU admission for respiratory failure,
recurrent hospitalizations,
severe dyspnoea (mMRC 4),
high prognostic index scores (e.g. BODE ≥7).



Eur Clin Respir J 2018

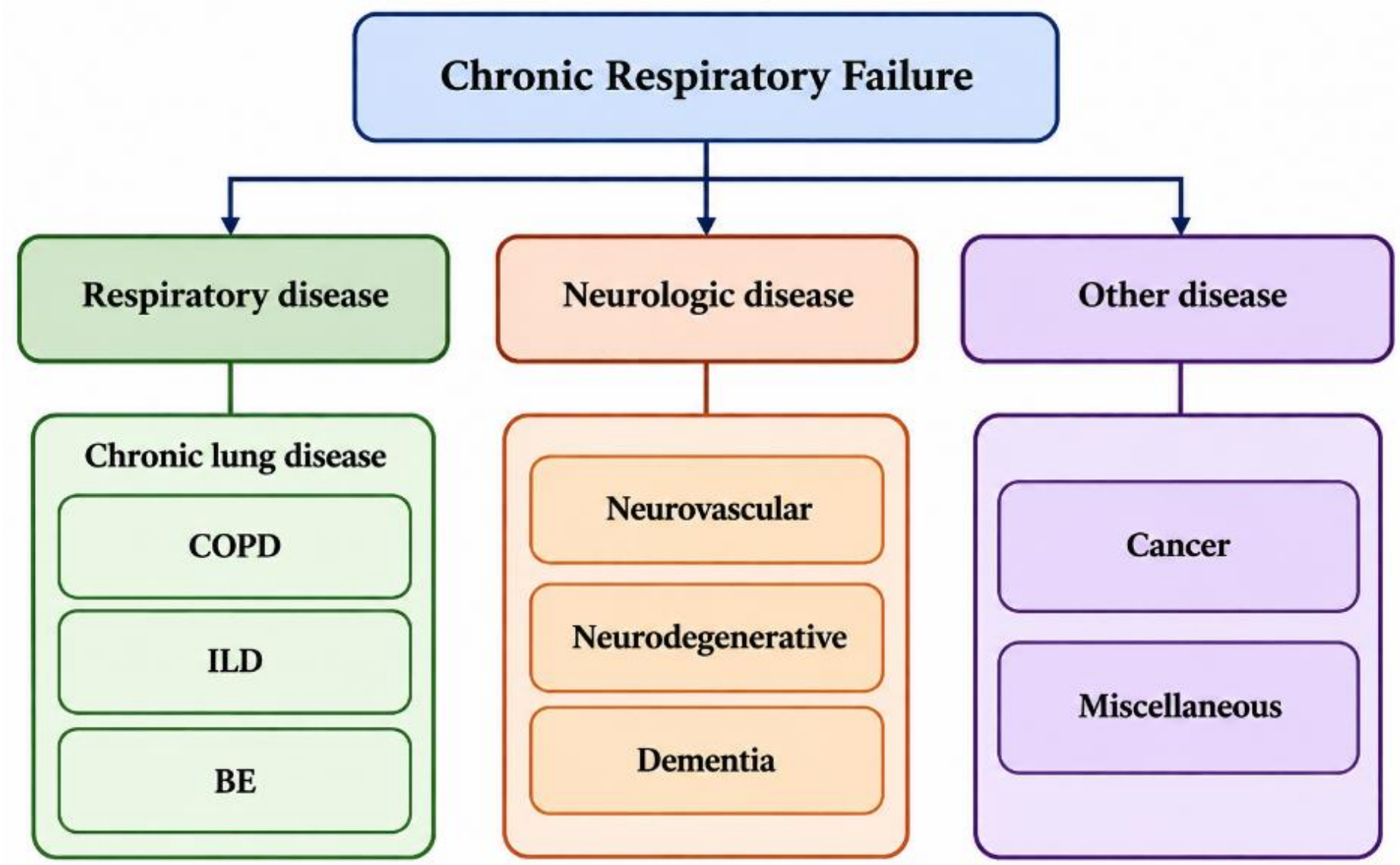
Index – Estabilished Concept

- Chronic respiratory failure
- Progressive Non-malignant lung disease
- Palliative treatment
- Advanced care plan

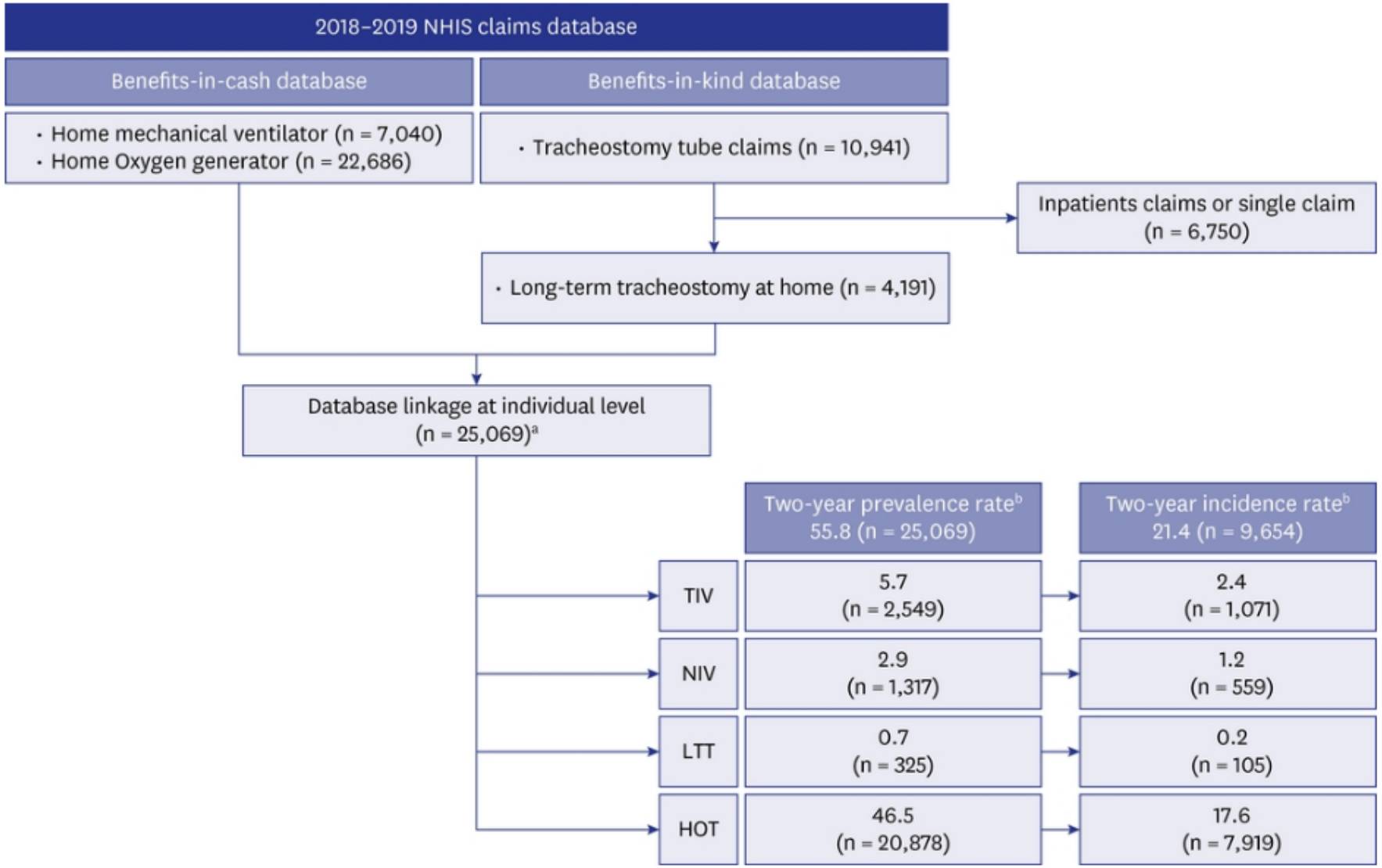
Index – Emerging Concept

- Chronic respiratory failure
- Progressive Non-malignant lung disease
- Palliative treatment
- Advanced care plan

- Chronic respiratory failure



Epidemiology and Characteristics of Patients Living at Home Using Home Mechanical Ventilation, Tracheostomy, or Oxygen Therapy: An Analysis of NHIS Claims Data in Korea



Epidemiology and Characteristics of Patients Living at Home Using Home Mechanical Ventilation, Tracheostomy, or Oxygen Therapy: An Analysis of NHIS Claims Data in Korea

Variables	Total (N = 25,069)	HMV			LTT (n = 325)	HOT (n = 20,878)	*P* value
		Subtotal (n = 3,866)	TIV (n = 2,549)	NIV (n = 1,317)			
Clinical characteristics							
Primary diagnosis[b]							< 0.001
Respiratory disease	17,489 (69.8)	1,180 (30.5)	671 (26.3)	509 (38.6)	209 (64.3)	16,100 (77.1)	
COPD	14,006 (55.9)	919 (23.8)	502 (19.7)	417 (31.7)	151 (46.5)	12,936 (62.0)	
Asthma	1,840 (7.3)	209 (5.4)	136 (5.3)	73 (5.5)	23 (7.1)	1,608 (7.7)	
Interstitial lung disease	1,643 (6.6)	52 (1.3)	33 (1.3)	19 (1.4)	35 (10.8)	1,556 (7.5)	
Neurologic disease	2,980 (11.9)	1,650 (42.7)	1,164 (45.7)	486 (36.9)	57 (17.5)	1,273 (6.1)	
Neurovascular	1,514 (6.0)	790 (20.4)	604 (23.7)	186 (14.1)	38 (11.7)	686 (3.3)	
Neurodegenerative[c]	992 (4.0)	786 (20.3)	516 (20.2)	270 (20.5)	16 (4.9)	190 (0.9)	
Dementia	474 (1.9)	74 (1.9)	44 (1.7)	30 (2.3)	3 (0.9)	397 (1.9)	
Cancer	1,947 (7.8)	108 (2.8)	73 (2.9)	35 (2.7)	19 (5.8)	1,820 (8.7)	
Miscellaneous[d]	2,653 (10.6)	928 (24.0)	641 (25.1)	287 (21.8)	40 (12.3)	1,685 (8.1)	

Provisional

Roadmap for Advancing a New Subspecialty in Pulmonary Medicine Devoted to Chronic Respiratory Failure

Michelle Cao[1], Sherri Lynne Katz[2], and John Hansen-Flaschen[3]

- "What Do We Mean by 'Chronic Respiratory Failure'?"
- In current practice, the term chronic respiratory failure is commonly used to identify children and adults who benefit from **long-term assisted ventilation to manage persistent hypercapnia.**

Condition	Examples
Congenital neuromuscular diseases	Spinal muscular atrophy, muscular dystrophies
Brain disorders	Cerebral palsy, congenital central hypoventilation syndrome
Adult-onset motor neuron diseases	Amyotrophic lateral sclerosis, multifocal motor neuropathy
Metabolic myopathies	Mitochondrial disorders, Pompe disease
Autoimmune neuromuscular diseases	Myasthenia gravis, chronic immune demyelinating polyneuropathy
Diaphragm paralysis	Amyotrophic neuralgia, traumatic or surgical phrenic nerve injury
Obesity hypoventilation syndrome	—
Chronic obstructive pulmonary disease	—
Spinal cord injury	—
Other conditions leading to chronic respiratory failure	Post–COVID-19 acute respiratory failure, chronic critical illness/prolonged mechanical ventilation

Definition of abbreviation: COVID-19 = coronavirus disease.

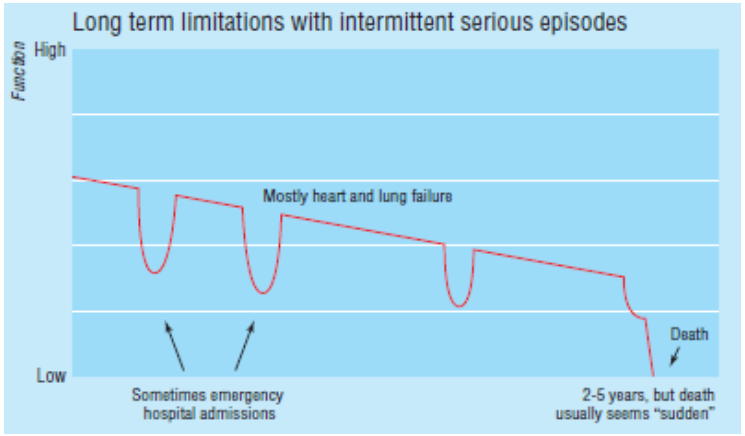
AnnalsATS 2024.Vol21Num5

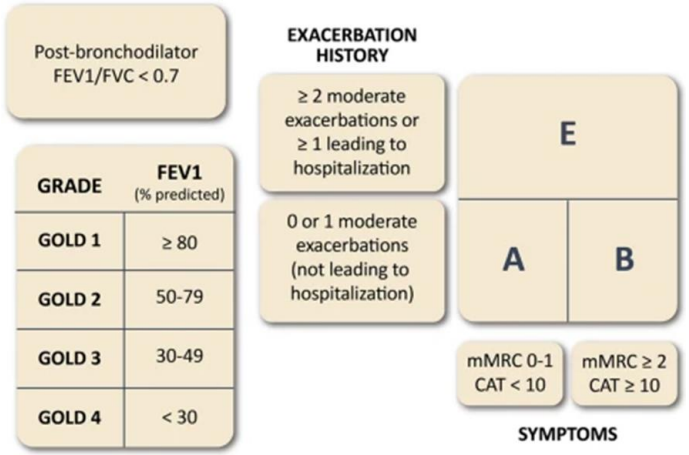
Advanced chronic respiratory disease

- **Advanced airway disease with**
  - Severe irreversible airflow limitation
  - Chronic respiratory failure (LTOT ± NIV)

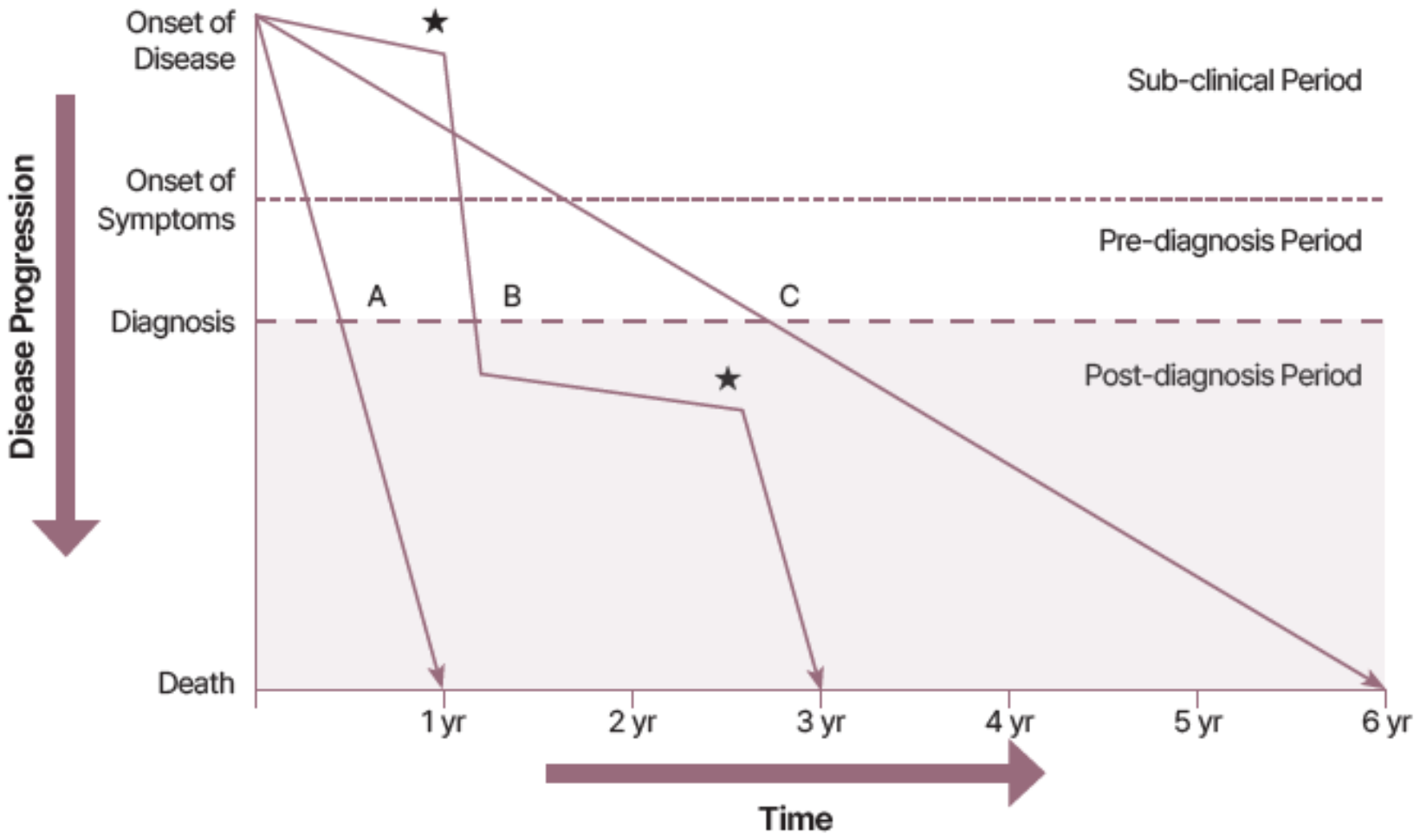
  - Refractory dyspnea and functional dependence

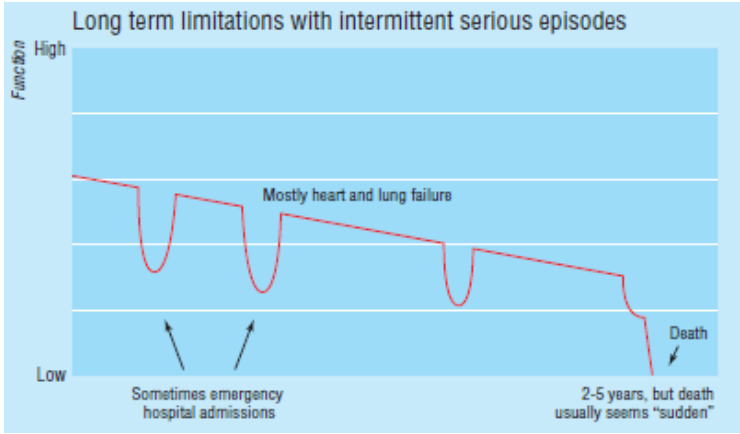
- Recurrent hospitalizations or ICU admissions
- Progressive decline despite maximal guideline-based therapy





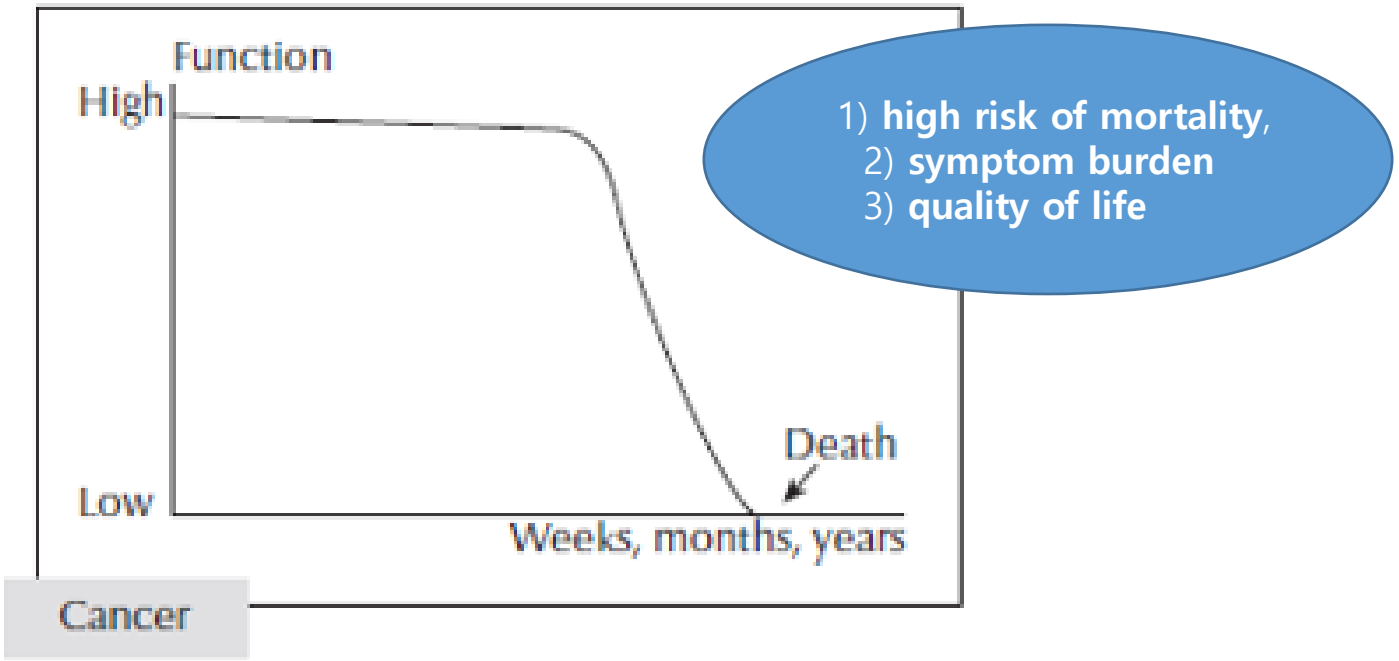
Disease progression of Idiopathic pulmonary fibrosis



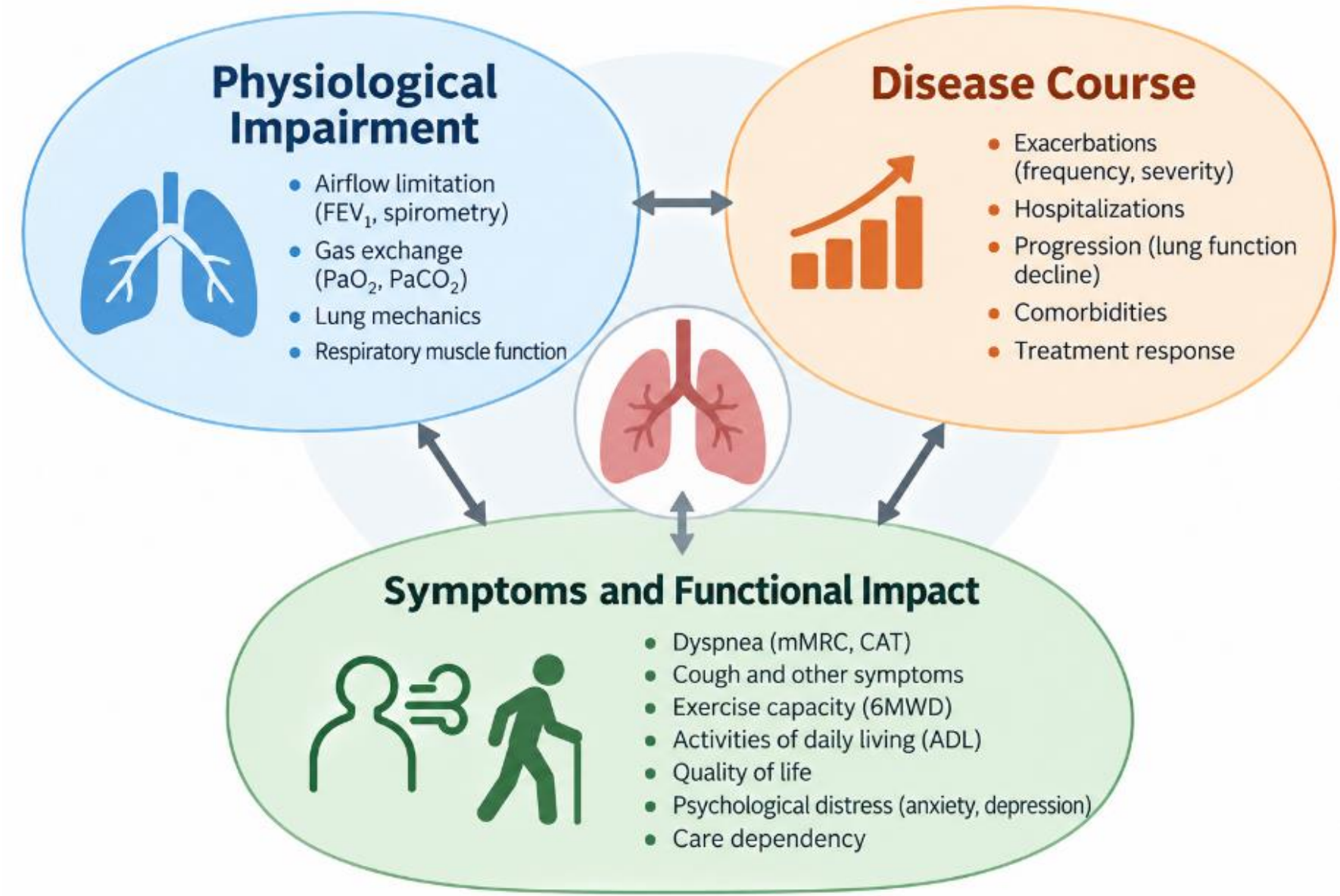


대한결핵 및 호흡기학회 간질성폐질환(ILD) 임상진료지침 2023

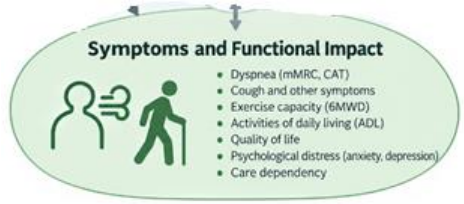
Advanced chronic respiratory disease



Advanced chronic respiratory disease



Symptoms and Functional impact



1. Non-pharmacological interventions



- Pulmonary rehabilitation and graded exercise
- Breathing techniques
- Handheld fan (cool air)
- Positioning and activity pacing
- Energy conservation

2. Pharmacological interventions



- Opioids: consider for refractory dyspnoea (not routine use)
- Corticosteroids: for steroid-responsive conditions
- Bronchodilators: if airflow obstruction
- Anxiolytics: for severe anxiety/panic
- Antitussives: for troublessone cough

3. Respiratory support



- Oxygen therapy (LTOT or ambulatory)
- Non-invasive ventilation (selected patients)
- High-flow nasal cannula (selected patients)

Palliative management for serious respiratory illness

(ERS 2024)

4. Psychosocial care



- Psychological support
- Anxiety and coping strategies
- Family and caregiver support
- Multidisciplinary care

5. Advance care planning



- Goals-of-care discussions
- Patient preferences and treatment limitations
- Early and repeated discussions

6. Specialist palliative care



- Comprehensive symptom assessment
- Coordination of care
- End-of-life support

ERJ 2024 63(6): 2400335

Disease course – Prognostic uncertainty



Prognostic uncertainty should not delay advance care planning
; rather, it should prompt it.

ACP is **not a prognostic exercise**,
but a **preparatory process** for uncertain future scenarios
> a justification for early and iterative conversations

Shift from prognosis-based to needs-based care
Practical alternative to End-stage definition
"Is this patient in the last 6–12 months of life?"
"Does this patient have unmet physical, psychological, social, or decisional needs?"

Eur Respir Rev 2024; 33: 240120

Needs-based Initiation of ACP from Prognosis-based

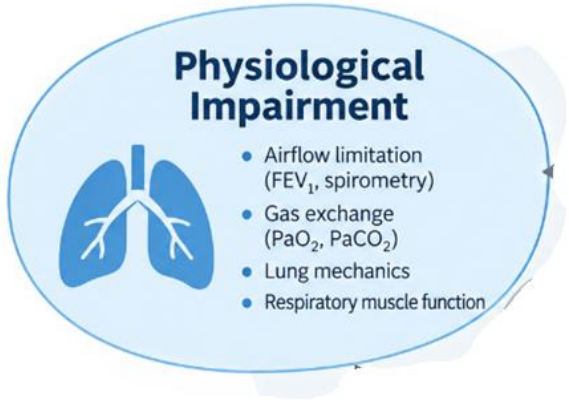


Clinicians should ask:
"Does this patient have unmet physical, psychological, social, or decisional needs?"

Needs-based criteria	Disease-based/health service utilisation criteria
Physical or emotional symptoms (*e.g.* poor symptom control, breathlessness, pain, weight loss, cachexia)	Hospital use (*e.g.* admission, frequency of admission, admission for exacerbation)
Functional decline (*e.g.* increasing care dependency, low 6-min walk test or gait speed, unable to meet ADLs)	Respiratory status (*e.g.* FEV_1 <30% pred, respiratory insufficiency, GOLD stage 3–4)
Psychosocial (*e.g.* social needs, supportive counselling, spiritual or existential concerns)	Advanced respiratory therapies (*e.g.* invasive/noninvasive ventilation, home oxygen use)
Decision support (*e.g.* ACP, hospice referral, care coordination)	Disease progression (*e.g.* deteriorating lung function, heart failure, low albumin, multimorbidity)
Person with illness or informal caregiver request for palliative care	Prognosis (*e.g.* "surprise question" [70], life expectancy <6–12 months)
Informal caregiver distress or need for support	Comorbidities (*e.g.* cancer, renal failure, diabetes)
Other (*e.g.* ethical concerns)	New diagnosis (ILD specific)
	End-stage care (*e.g.* terminal care, lack of treatment options)
	Other (*e.g.* frailty)

Eur Respir Rev 2024; 33: 240120
Eur Respir J 2023; 62: 2202014

Physcial impairment – chronic respiratory failure



Ambulatory oxygen: why do COPD patients not use their portable systems as prescribed? A qualitative study

Perceived / Internalized Stigma
Shame · Embarrassment · Fear of judgment

↓

Stigma Coping Strategies
Social support · Reframing · Self-advocacy

↓

Acceptance and Identity Reconstruction
Accepting illness without defining oneself by it

↓

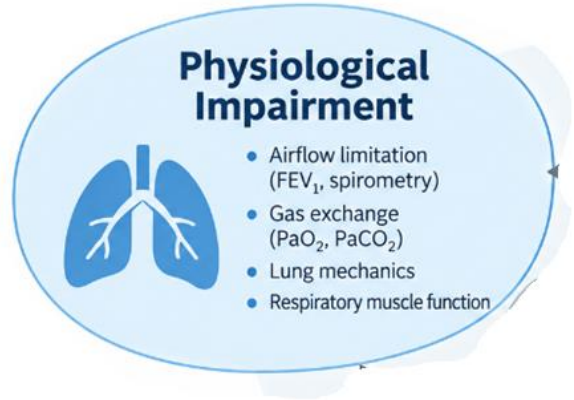
Normalization and Social Reintegration
Integrating respiratory support into everyday life

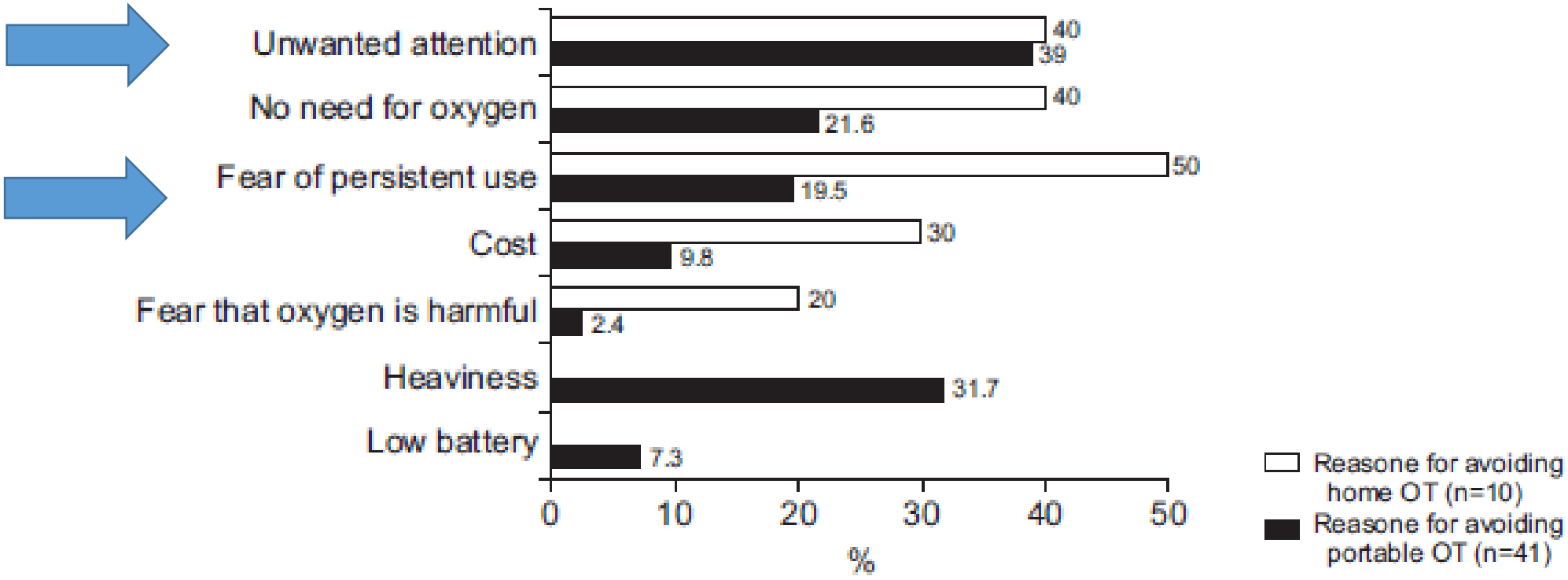
Arnold et al. BMC Pulmonary Medicine 2011, 11:9

trd Tuberculosis & Respiratory Diseases

Perception of Long-Term Oxygen Therapy for Chronic Lung Diseases May Affect Poor Adherence in Korea

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2005-6184(Online)
Tuberc Respir Dis 2024;87:100-114





The Limited Value of Dementia-Specific Advance Directives

Hastings Cent Rep. 2021 Mar;51(2):4-5.

by Rebecca Dresser



- Professor of Law, and Professor of Ethics in Medicine Washington Universi

Palliative Care for Patients with Terminal Dementia*

말기치매 환자의 완화의료*

생물치료정신의학 제 17 권 제 2 호, 2011
J Korean Soc Biol Ther Psychiatry Vol 17, No 2, 2011

진행된 치매는 완화의료를 필요로 하는 말기 상태이며, 이는 치매 진단의 시점에서 부터 시작되어야 한다. 그러나, 치매의 임종 의료는 부진한 형편이다.

말기 단계의 치매에서 의식 수준, 눈 접촉, 언어, 근육의 유연성, 삼키기의 장애 뿐만 아니라 음식섭취의 감소와 체중상실도 죽어가는 과정의 시작에 대한 지표이다.

말기 치매 환자의 임종의료에서 평안과 존엄성의 유지가 중요하다.

치매·인지 기능 저하에 따른 사전 돌봄 계획(Advance Care Planning)의 필요성과 실천 과제

보건사회연구 39(3), 2019, 041-072
Health and Social Welfare Review
http://dx.doi.org/10.15709/hswr.2019.39.3.41

치매 돌봄 현장에서 근무하는 사회복지사 7명을 심층 면담하였으며, 주제별 분석 방법으로 연구 결과를 분석하였다. 분석 결과, 연구참여자들은 건강할 때 당사자 스스로 돌봄에 대한 의사를 결정할 수 있으며, 사전에 미래를 준비하여 안정감을 느끼고, 무의미한 연명치료를 방지할 수 있다는 점에서 치매·인지 기능 저하에 따른 사전 돌봄 계획의 필요성에 공감하였다. 그러나 당사자 및 가족이 느끼는 인지 저하와 신체적 죽음

The Limited Value of Dementia-Specific Advance Directives

Hastings Cent Rep. 2021 Mar;51(2):4-5.

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that advance directives are often made under conditions of **severe epistemic limitation**.
Individuals without dementia routinely misjudge what life with cognitive impairment will actually be like.
Many people adapt to conditions they previously believed would be intolerable.
Preferences expressed in advance therefore may not reflect what the person would choose **if they had accurate experiential knowledge**.
From this perspective, advance directives about dementia risk being based on **fear, stigma, or false assumptions**, rather than informed understanding.

(1) 치매 환자는 여전히 **기쁨을 느끼고,**
즐거움을 경험하며, 관계를 맺는다
건강한 상태에서 상상한 "치매 상태의 나"는
실제 치매 상태의 경험과 **극적으로 다를 수 있음**

(2) '정체성의 연속성'은 생각보다 약하다
치매가 진행되면 가치관, 성격, 관심, 관계 인식이 **근본적으로 변할 수 있음**

(3) 사전의료계획은 미래를 제대로 예측하지 못한다.
따라서 사전 지시는 **정보 부족 상태에서의 결정**
"현재의 환자를 '무지한 과거의 계획을 실행하기 위한 도구'로 전락시킨다"

The Limited Value of Dementia-S Directives

by Rebecca Dresser

- Professor of Law, and Universi

that advance directives a
conditions of **severe epi**
Individuals without dem
life with cognitive impair
Many people adapt to c
believed would be intole
Preferences expressed in
reflect what the person
accurate experiential kn
From this perspective, ac
dementia risk being bas
assumptions, rather tha

formation, describing symptoms associated with different stages of dementia and the types of treatment issues that can arise. But the directives focus almost exclusively on the negatives. For example, a widely publicized form lists only the losses and impairments that occur. It says nothing about the abilities that people retain, including the contentment, relationships, and even joy that people experience, particularly if they are living in settings respectful of their needs and interests.[9] None of the directives refer to supplementary educational materials, such as accounts by people living with dementia or by their family and professional caregivers.[10]



서전히 **고통을 느끼고,**
험하며, 관계를 맺는다
서 상상한 "치매 상태의 나"는
태의 경험과 **극적으로 다를 수 있음**

성'은 생각보다 약하다
면 가치관, 성격, 관심, 관계 인식이 **근본**
음

은 미래를 제대로 예측하지 못한다.
시는 **정보 부족 상태에서의 결정**
'무지한 과거의 계획을 실행하기 위한
도구'로 선택지간다"

Standard Model of ALS and Long-Term Ventilation









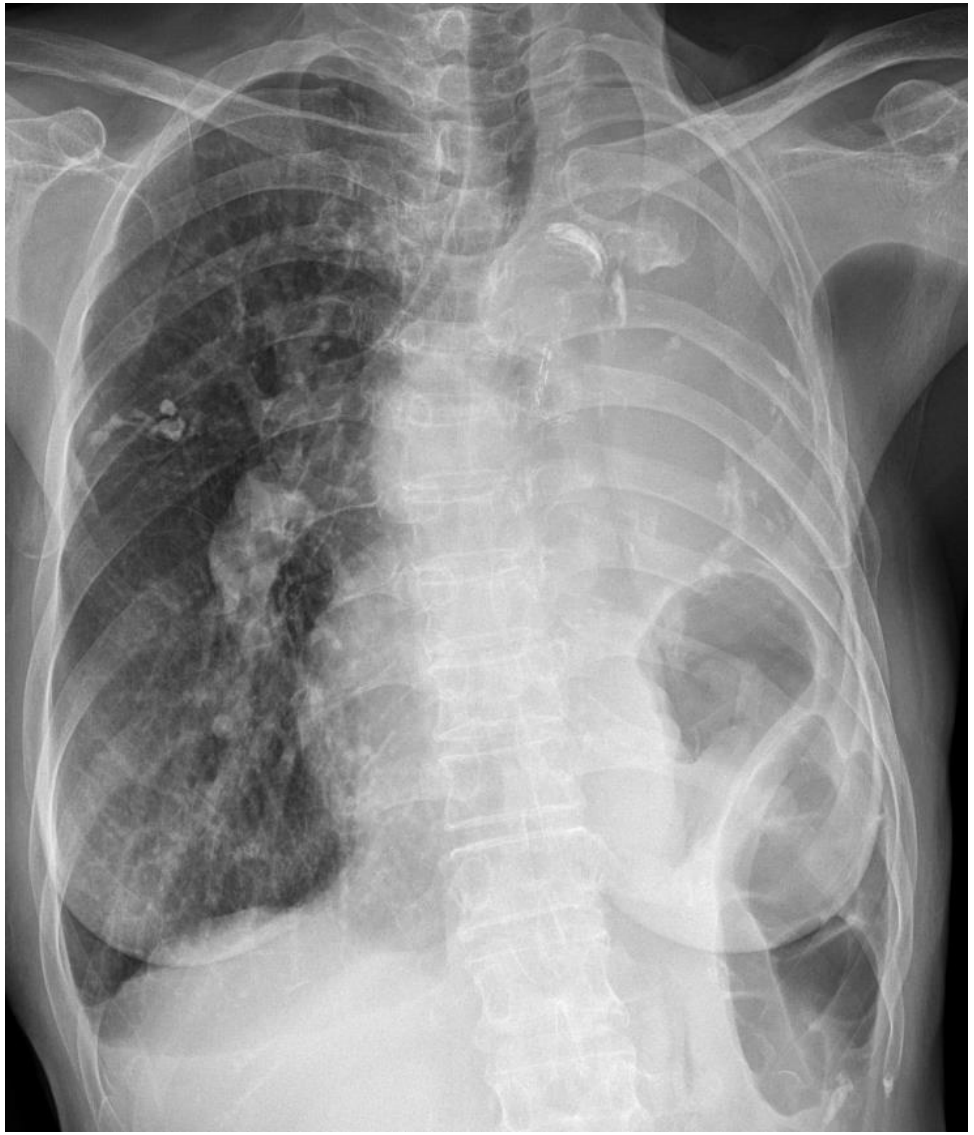




Case5. F/67 Dyspnea

- TB destroyed lung 로 호흡기 내과에서 재택 산소 및 비침습성 인공호흡기 사용 중인 자로, 내원 3일전부터 호흡곤란이 심해지고 전신 쇠약감이 심해지면서 산소를 사용중에도 산소포화도가 감소되어 내원함.

Blood gas - pH	▼7.220	
Blood gas - pCO2	▲116	mmHg
Blood gas - pO2	▼68.4	mmHg
Blood gas - Base excess,ECF	▲19.8	mmol/L
Blood gas - Base excess	▲16.0	mmol/L
Blood gas - Bicarbonate,std	▲39.9	mmol/L
Blood gas - Bicarbonate,act	▲47.5	mmol/L
Blood gas - Total CO2	▲46.1	mmol/L
Blood gas - O2 saturation	90.7	%
Blood gas - O2 content	▼5.7	mmol/L
Blood gas - Anion gap. K	7.5	mmol/L
Ionized Ca, Blood gas	1.20	mmol/L
Ionized Ca,normalized	1.08	mmol/L
Lactic acid, Blood gas	▼0.3	mmol/L



Case5. F/67 Dyspnea

- TB destroyed lung 로 호흡기 내과에서 재택 산소 및 비침습성 인공호흡기 사용 중인 자로, 내원 3일전부터 호흡곤란이 심해지고 전신 쇠약감이 심해지면서 산소를 사용 중에도 산소포화도가 감소되어 내원함.

		PRED	PRE-RX_BEST	PRE-RX_%PRED
FVC	Liters	2.94	0.73	25
FEV1	Liters	2.31	0.41	18
FEV1/FVC	%	77	56	
FEF25-75%	L/sec	2.25	0.21	9
PEF	L/sec	5.28	1.50	28
PIF	L/sec		0.74	
FET100%	Sec		5.11	
MVV	L/min	86		

* Total distance walked in 6 minutes - 120(m)
  Number of laps 2 (*60 meters) + Final partial lap 0 (meters)

* Minimal SpO_2 during exercise - 86(%)

**Insihgt(+) 본인/남편:폐질환으로 인한 심장기능장애(우심부전)
: 예후가 불량하며 폐이식이외에 치료 방법은 없으나 치료 예후는 불량함. (양산부산대 교수님과 상담)
** Saturation(RA)84%-HomeO2 사용시2L: 96%
NIV (2019.5) > PSV(2025.5): IPEP18-EPAP4 RR 16 : MV5L/m 이상을 목표로.
Home O2(2020.3.18) 0.5 / 1.5(NIV시) (매년 2.25-)

검사명 (*:중간보고)	결과	단위
Blood gas - Hb	10.0	g/dL
Blood gas - Hct	29	%
Blood gas - pH	7.358	
Blood gas - pCO2	70.9	mmHg
Blood gas - pO2	29.3	mmHg
Blood gas - Base excess,ECF	13.5	mmol/L
Blood gas - Base excess	11.4	mmol/L
Blood gas - Bicarbonate,std	34.0	mmol/L
Blood gas - Bicarbonate,act	39.0	mmol/L
Blood gas - Total CO2	41.2	mmol/L
Blood gas - O2 saturation	43.3	%
Blood gas - O2 content	2.7	mmol/L
Blood gas - Anion gap. K	13.3	mmol/L
Ionized Ca, Blood gas	1.14	mmol/L
Ionized Ca,normalized	1.12	mmol/L
Lactic acid, Blood gas	1.13	mmol/L

Case5. F/67 Dyspnea

End-Stage lung disease

입원일자	HD	Dept
2026-06-04	15	PUL
2026-03-28	6	PUL
2025-04-17	21	PUL
2024-04-14	6	PUL
2024-02-07	3	PUL
2024-01-02	5	PUL
2023-06-25	11	PUL
2022-07-17	17	PUL
2019-12-23	9	PUL
2019-11-11	5	PUL
2019-04-28	44	PUL
2017-12-03	7	PUL
2017-07-08	14	PUL
2017-04-12	11	PUL
2016-12-19	19	PUL
2016-09-10	10	PUL
2016-05-09	10	PUL

#2. TB destroyed lung
#7. Rt Heart failure
-> PAH d/t Chronic lung disease (TB Destroyed lung)
: Echo (2017.4.14->6.23) PAP >55.6mmHg Lasix /aldactone
PFT (2016.6.21) : 51% 0.50 (20%) / 0.96(32%)
ANA/ANCA/RA/antiCCP (N/N/N/N:2017.7.12)
ICS/LABA + Home O2, singular (FOSTer)
diuretic 조절
47kg (2017.4.28) 46kg(2017.6.23)45.1kg (2017.7.31)

**Insihgt(+) 본인/남편:폐질환으로 인한 심장기능장애(우심부전)
: 예후가 불량하며 폐이식이외에 치료 방법은 없으나 치료 예후는 불량함. (양산 부산대 교수님과 비공식 상담)

환자의 Co2 retension 은 PAH d/t crhocni lung disease (TB destroyed lung) 으로 인한 V/Q mismatch 로 인한 증상이라 여겨짐
Diuretics / Oxygen / anti platelet
-> 증상 및 Echo 악화.
: 보호자 (남편) - 향후 장기적으로 불량한 예후 설명.
명확한 의학적 근거가 있는 치료약제는 현재 없음.
결국 폐/심장 이식이 필요할 수 있음.
상급 의료기관 상담 권유.
임종기 관리 - 향후 연명치료 등에 대해 상담.

Case. F/67 Dyspnea

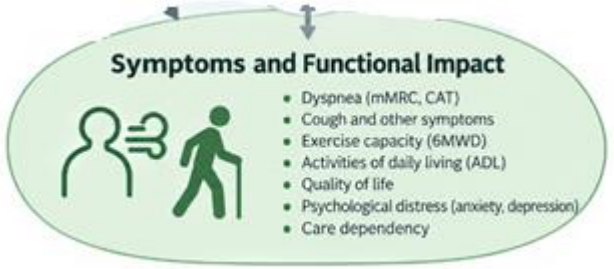
입원일자	HD	Dept
2026-06-04	15	PUL
2026-03-28	6	PUL
2025-04-17	21	PUL
2024-04-14	6	PUL
2024-02-07	3	PUL
2024-01-02	5	PUL
2023-06-25	11	PUL
2022-07-17	17	PUL
2019-12-23	9	PUL
2019-11-11	5	PUL
2019-04-28	44	PUL
2017-12-03	7	PUL
2017-07-08	14	PUL
2017-04-12	11	PUL
2016-12-19	19	PUL
2016-09-10	10	PUL
2016-05-09	10	PUL

■ Comment
**Insihgt(+) 본인/남편:폐질환으로 인한 심장기능장애(우심부전)
: 예후가 불량하며 페이식이외에 치료 방법은 없으나 치료 예후는 불량함. (양산부산대 교수님과 상담)
** Saturation(RA)84%-HomeO2 사용시2L: 96%
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Home O2(2020.3.18) 0.5 / 1.5(NIV시)
** ABGA 가 불가해서 정확히 평가하기 힘드나, VBGA 와 pH 0.06, CO2 15 차이.
NIV를 하고 아침에 일어나면 VBGA 7.33 79.2 35.7 63% > ABGA 7.39 65 내외로 추정
NIV 없이 지낸 후 취침전 VBGA 7.24 94.6 41.7 97% > ABGA 7.30 80 내외로 추정.
** 위의 사실을 설명한 후 향후 심폐기능 악화시 Tracheosotmy 를 통해 NIV 적용을 강력히 권유함. 입원 중 여러차례 설명하여 취지는 이해하나 명확한 의사를 밝히지 않음.

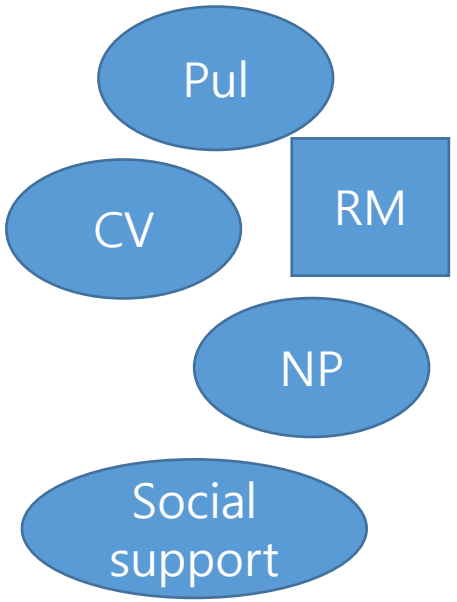
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** Saturation(RA)84%-HomeO2 사용시2L: 96%
NIV (2019.5) > PSV : IPEP16-EPAP5)
** HomeO2(1.5L/m in: 2020.3.19)
* Jublia / 45kg (2022.5.17) 고성 > 43.5kg(2022.10.21)

** headache 등 CO2 retension 증상의심되어 입원 후 IPAP/EPAP 13/4 - 16 -> (16/5 -8) 후 증상호전(2022.8.9)
** 최근 BiPAP 잘 안썼다... CO2 retenison
: adm 권유 > BiPAPA잘 써보고 호전없으면 입원하겠다.

** End stage lung diseaes 이지만, 나이가 젊고, 이전에 악화후 호전된 경험이 있어서 연명의료에 대한 결정은 다시 상의.



Palliative Therapy



Case. F/67 Dyspnea

입원일자	HD	Dept
2026-06-04	15	PUL
2026-03-28	6	PUL
2025-04-17	21	PUL
2024-04-14	6	PUL
2024-02-07	3	PUL
2024-01-02	5	PUL
2023-06-25	11	PUL
2022-07-17	17	PUL
2019-12-23	9	PUL
2019-11-11	5	PUL
2019-04-28	44	PUL
2017-12-03	7	PUL
2017-07-08	14	PUL
2017-04-12	11	PUL
2016-12-19	19	PUL
2016-09-10	10	PUL
2016-05-09	10	PUL



■ Comment

** 환자/배우자

원래 심폐기능이 나빠서 여러차례 상태 악화시 기도삽관 및 인공호흡기 사용할 가능성이 있다고 설명하였으나 뚜렷한 대답은 하지 않았던 상태.

보통 '이렇게 살다가 가야지요'라고 하면서도 실제로 응급실로 오면 의사의 지시대로 모두 하겠다고 이야기하는 상태.

현재 뚜렷한 악화인자(폐렴등)이 보이지 않는 상태에서 호흡기능이 악화된 상태라서 기도삽관 및 인공호흡기 사용과 필요시 (가능성 높음) 기관절개를 통해 인공호흡기 사용을 권하였으나 뚜렷한 의사를 밝히지 않음.

환자와 보호자는 환자의 심폐상태에 대해 알고 있으나 연명치료등에 대한 결정을 외면하고 있어 환자 상태 악화시 Intubation 과 ICU 전실등이 원칙대로 진행될 것이라고 설명하였습니다.

Advanced Care Plan

<Patient Values and Preferences>

** 본인(+) 배우자(남편) 자녀(-) 동생

환자는 TB destroyed lung 을 20대 부터 가지고 있는 환자로 2016년부터 Home O2, 2019년부터 NIV 를 사용하면서 안정시에 pH7.3 초반/CO2 80 이상이 유지되는 만성호흡부전 환자임.

> 이로 인해 가벼운 전신상태 악화시에 쉽게 호흡부전(주로 resp.acidosis악화)가 일어남

> 환자는 오랜기간 투병기간을 통해 환자의 호흡상태를 잘 이해하고 있고 향후 호전을 기대하기 힘들며 이로인해 호흡부전이 발생하면 인공호흡기 등의 치료가 필요할 수 있다는 사실을 이해하고 있음

하지만, 아직 일상활동 능력이 매우 원활하고 적극적인 삶의 의지를 보여 인공호흡기등의 적극적인 치료를 원하고 있음. (하지만, tracheostomy 에 대해 부정적. 반드시 필요할 수있음을 설명)

: 본인과 배우자(남편)는 환자의 선호를 공유하며 향후 대리의사가 필요할시 남편의 의견을 따르기로 함.

Case. F/67 Dyspnea

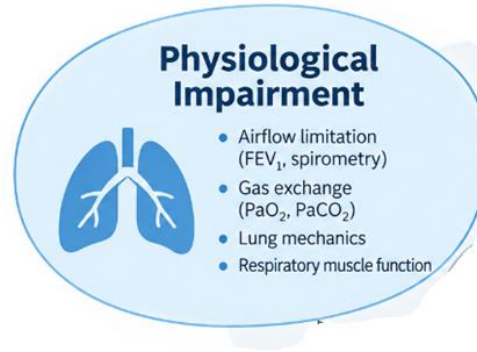
입원일자	HD	Dept
2026-06-04	15	PUL
2026-03-28	6	PUL
2025-04-17	21	PUL
2024-04-14	6	PUL
2024-02-07	3	PUL
2024-01-02	5	PUL
2023-06-25	11	PUL
2022-07-17	17	PUL
2019-12-23	9	PUL
2019-11-11	5	PUL
2019-04-28	44	PUL
2017-12-03	7	PUL
2017-07-08	14	PUL
2017-04-12	11	PUL
2016-12-19	19	PUL
2016-09-10	10	PUL
2016-05-09	10	PUL

Opinion)
환자는 만성폐질환(TB destroyed lung)의로 인한 우심부전 환자로 Home O2(0.5)와 nocturnal NIV를 사용 중입니다. 최근 가벼운 stress (URI 등)에도 증상 악화가 자주 반복되어 말기 상태로 판단되나, 환자가 삶에 대한 의지가 강하여 적극적인 치료를 원합니다.

본인/배우자 면담(2026.6.15)
이전 입원에 비해 이번 입원에는 악화인자(폐렴 등)이 보이지 않음. 보통 입원 후 2-3일이면 평소 ABGA 로 회복이 되나(그래도 정상치의 하안선: pH7.30) 이번에는 입원 후 2주 정도가 지나고 있으나 ABGA(정확히VBGA) 수치가 이전에 비해 나쁜 편임.
아마, 이전에 비해 심폐기능이 점차 떨어지고 있는 상태로 보임.

이 경우, 마스크 인공호흡기(NIV)만으로는 충분한 호흡을 만들어 줄 수 없어 기관절개 후 인공호흡기를 사용하는 것을 권유함.
기관절개를 한다해도 일상활동과 식사가 가능하고 인공호흡기를 떼고 있을 때는 일부장비의 도움을 받아 말을 할 수 있어서 일반적인 말기환자와는 삶의 질이 보장됨. 기관절개를 단순히 치료실패나 장애로 보지 말고 새로운 호흡장치로 생각해 보기를 권함.

아직은 환자 본인이 기관절개를 하지 않았을 때의 위험을 알지만 기관절개를 원치 않고 있어서 위의 사항을 충분히 설명 후 퇴원하고, 한달정도 후 재입원하여 다시 심폐기능을 평가해 본 후 가급적 기관절개를 고려해 보시도록 권함. (2026.6.15)(2026.6.16)



Stigma coping strategy

Identity Reconstruction

Take-Home Messages

1. Chronic Respiratory Failure ≠ Terminal Disease

- A physiological condition arising from diverse diseases, not limited to pulmonary disorders.

2. Advanced Respiratory Disease Is Multidimensional

- Physiological impairment, symptom burden, and disease trajectory are distinct but interrelated dimensions—not necessarily present together.

3. Palliative Care Requires Respiratory Expertise

- Integrate disease-specific respiratory treatments with symptom relief and multidisciplinary care.

4. ACP Should Be Needs-Based, Not Prognosis-Based

- Initiate ACP according to patients' needs, values, and goals—not predicted survival or proximity to death.