

Engaging Patients and Family Members in ACP Conversations:

*The Local Experience of End-of-Life Care for People
Touched by Chronic Obstructive Pulmonary Disease*

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尊重生命 • 改變生命



★ Learning outcomes

After this lecture, participants should be able to

- 1. Understand relevance of **disease trajectory** in ACP conversation
- 2. Identify the **triggers** & the **barriers** for ACP
- 3. Understand **specific treatment options** addressed in ACP
in people with ***advanced COPD*** and their families

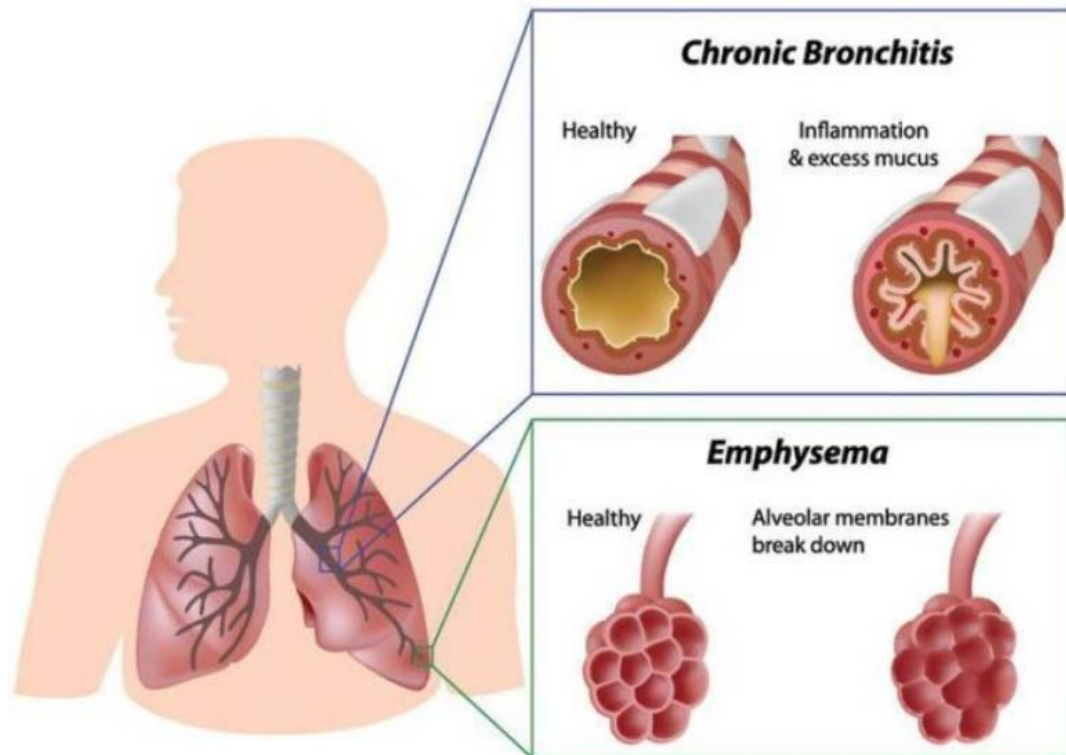


Contents

- 1. Advanced COPD
 - Disease management, severity, trajectory and palliative care needs
- 2. Advance care planning in advanced COPD
 - Triggers
 - Contents - Patient's views
 - Barriers
 - Sharing of HHH PC service for advanced COPD and ACP findings



Chronic Obstructive Pulmonary Disease (COPD)



<https://openairways.com/wp-content/uploads/2022/03/COPD-visual.jpg>

Irreversible

Causes

- Smoking, air pollutants/ chemicals, genetic factors

Key facts

- WHO
 - 3rd leading cause of death worldwide
 - Global prevalence: 250 millions (2016)
 - Death: 3.23 million (2019)
- HK
 - ~30000 admissions/year
 - 1200+ death in 2017



COPD – management

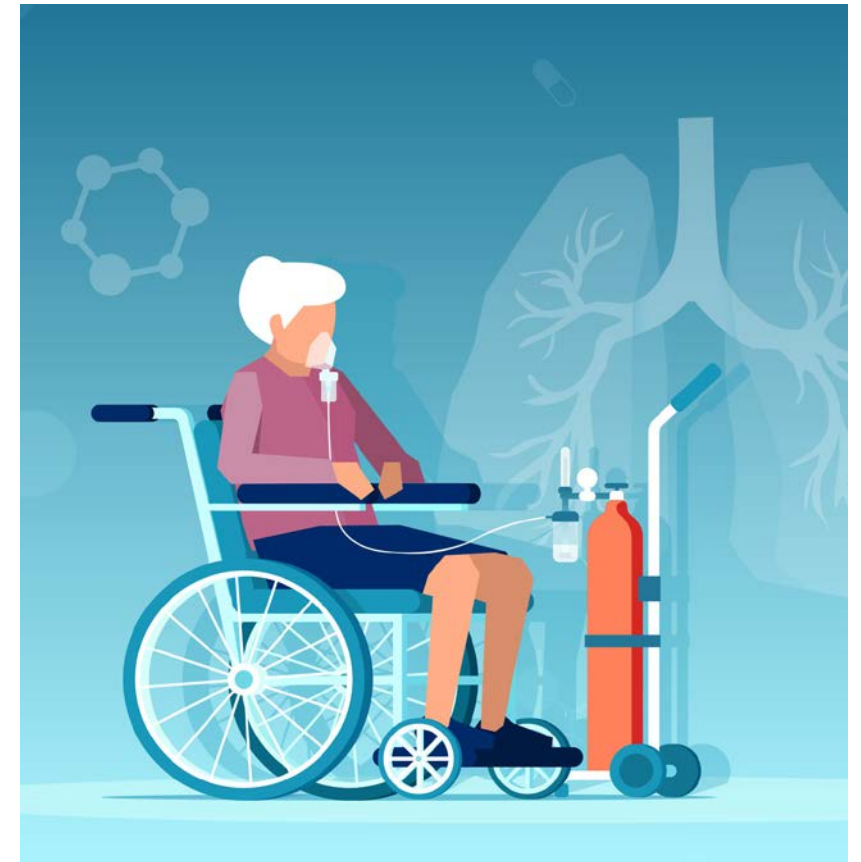
2023 GOLD Report -
Global Initiative for
Chronic Obstructive
Lung Disease - GOLD



Defining advanced COPD

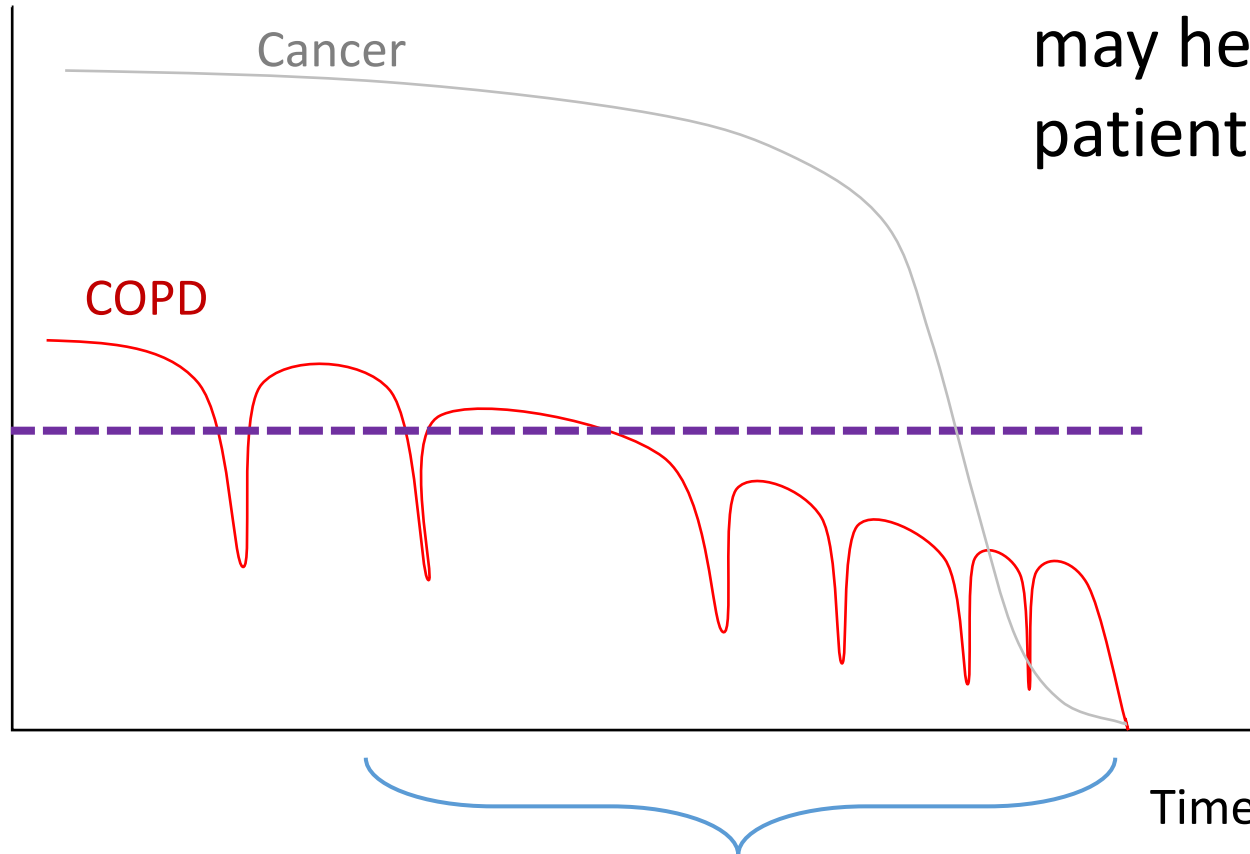
Specific clinical indicators including

- Severe disease (e.g., FEV1 <30% predicted by lung function test)
 - Required long term oxygen
 - Required ventilatory support
 - Recurrent hospital admissions (at least 3 in last year due to COPD)
 - Persistent symptoms e.g., breathlessness despite optimal therapy
- Gold Standards Framework (GSF) 2022
<https://goldstandardsframework.org.uk/>



Disease trajectories

Functional status



Introducing the trajectory to **acknowledge uncertainty** and may help **prevent surprises** to patients and families

Independence

Time

Uncertainty: Years? Months?



Advanced COPD vs. Advanced CA Lung

- **Worse quality of Life in COPD**

- Overall distress and **dyspnoea** (and for longer duration)
- **Depression** and **anxiety**
- Physical/ Social **functioning**

Gore 2000; Habraken 2009; Weingaertner 2014

- **Received less palliative care in COPD**

- **Less symptom-relief medication**: opioids and benzodiazepines
- **More diagnostic tests and life-prolonging measures**

Au 2006; Gore 2000; Hyasat 2015

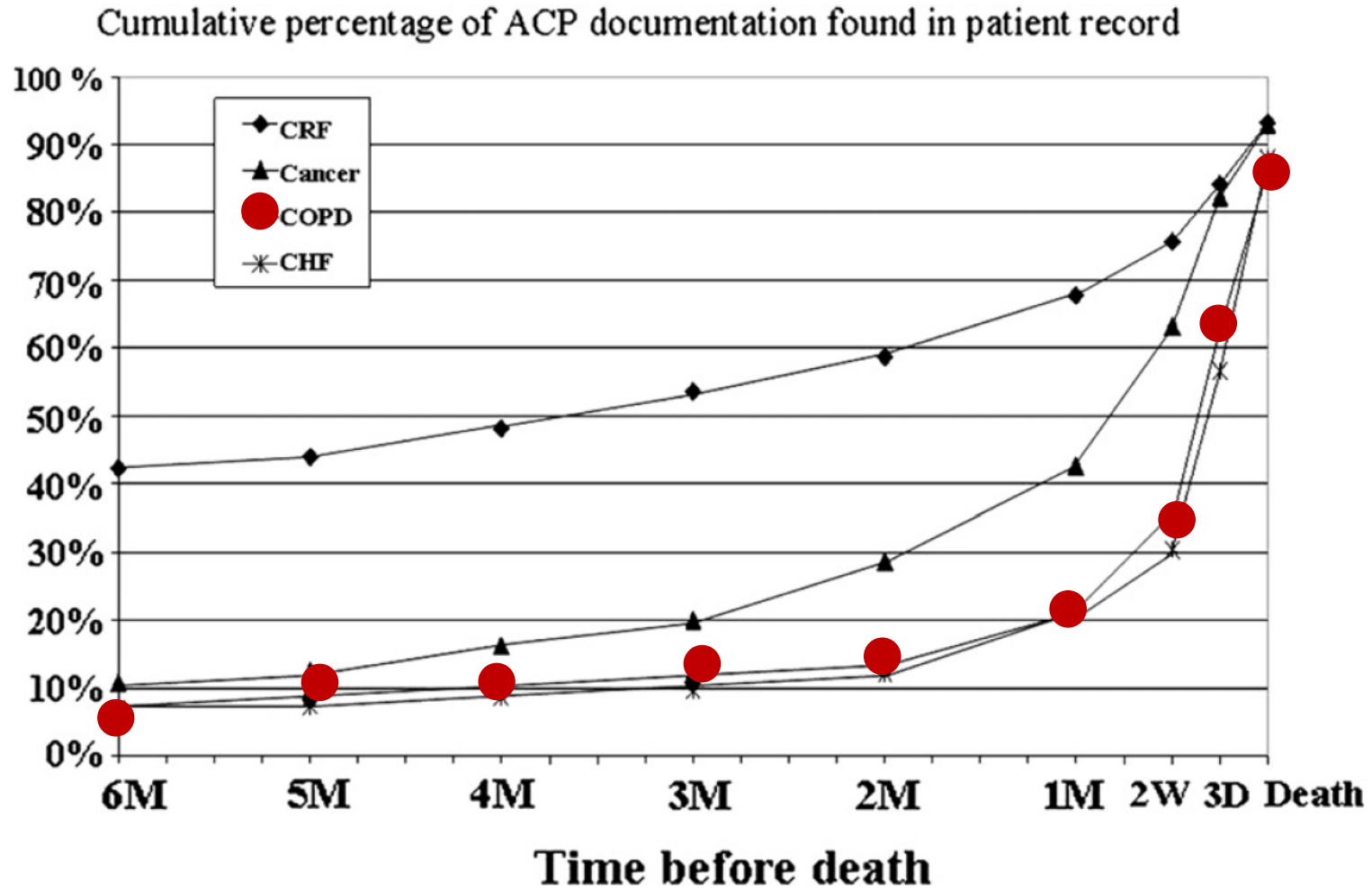


Advance Care Planning (ACP)

- Recommendations:
 - Informing patients about their **disease trajectories and prognoses**
 - Filling out **important documentation**
 - Sharing that information with **family members** and other **health care providers**
 - Tailored to the **patient's level of understanding** and **personal values**
 - Initiated with aging or **progression of the disease process**
- Rietjens JAC, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care (EAPC). *Lancet Oncol.* 2017;18(9):e543-e551.



ACP



Note: M = month, W = week, D = day

Lau KS, et al. Comparing Noncancer and Cancer Deaths in Hong Kong: A Retrospective Review. *J Pain and Sympt Manage* 2010, 40(5): 704 – 714.



Triggers for ACP in COPD

- Disease severity:
 - FEV1 < 30% of predicted
 - Dependence on oxygen
 - ≥1 hospital admissions in the past year for a COPD exacerbation
- General health factors
 - Left heart failure or other severe comorbidities
 - Weight loss or cachexia
 - Decreased functional status, increasing dependence on others, or
 - Being > 70 years old

• Curtis 2008

Predicting risk of death in COPD – BODE index

- Body mass
- Airway Obstruction
- Dyspnoea
- Exercise capacity

=> Predict 5-year survival

Celli et al. NEJM 2004.



What are the concerns affecting decision making in COPD?

19 advanced COPD patients + 49 case review in 2 hospitals in HK

3 factors affecting patient's decision making

Existential concerns

The will to live
Life values
Death & dying concerns

Burden of illness

Treatment burdens
Symptom burdens
Care burdens

Prognostic awareness

Physiological parameters
Performance status
Concomitant diseases
Therapeutic regimens
Utilization of medical services

Pang. *J Critical Care* 2004;19(3):135



Life sustaining treatment discussed in ACP in advanced COPD

Different indications in COPD

Non-invasive ventilation (NIV)

無創通氣治療/非侵襲性呼吸器

For respiratory failure

Endotracheal intubation

氣道插管

For respiratory failure

Cardiopulmonary resuscitation (CPR)

心肺復甦術

When cardiac arrest



Non-Invasive Ventilation (NIV)

- For improving survival:
 - Clear indication in specific conditions
- For relieving dyspnoea:
 - Possible mechanism - Decreases the work of breathing and allows respiratory muscle to rest
 - Evidence - limited
 - COPD: Lack strong evidence
 - Systematic review of 4 RCTs on COPD exacerbation (Smith et al., 2012)



Concerns

- Contra-indications of NIV
- Labour-intensive
- Skilled respiratory care
- Burdensome to patient and family
- ? Prolong dying process



Approach to using NIV in acute respiratory failure

- Reaching consensus in **goals of NIV** between patient, family and clinical team
- Setting “**end-points**” if possible

Category	1	2	3
Goals of NIV	Life Support Without Preset Limit	Life Support with Preset Limit (DNI)	Comfort Measures Only
Implication	Proceed to intubation if failed NIV	Not to proceed to intubation if failed NIV	Stop NIV if NIV causes discomfort

Non Palliative Care

Palliative Care

Palliative Care

- ▶ Curtis. Noninvasive positive pressure ventilation in critical and palliative care settings: Understanding the goals of therapy**Crit Care Med* 2007.



Potential barriers to ACP in COPD

- Patient/ families
 - **Inadequate understanding** about their disease and prognosis (trajectory)
 - Belief that **health-care professionals will initiate discussions** about end-of-life care at the appropriate time
 - Lack of **trusted** relationship with care providers
 - Preference for more **generalized discussion** about ACP rather than fixed decisions
- **Gott 2009; Janssen 2012; MacPherson 2013**



Barriers to communication in COPD

- Health-care professionals' barriers
 - Insufficient **time** and communication **skills (training)**
 - Uncertainty around **prognosis**
 - Feeling that end-of-life discussions **conflict with disease management**
 - Not wanting to **dispel hope**
- **Gott 2009; Janssen 2012**

Lack of system implementation

- Aligned triggers or indexes to initiate ACP discussion
- Interdisciplinary collaboration
- ACP clinic/ consultation



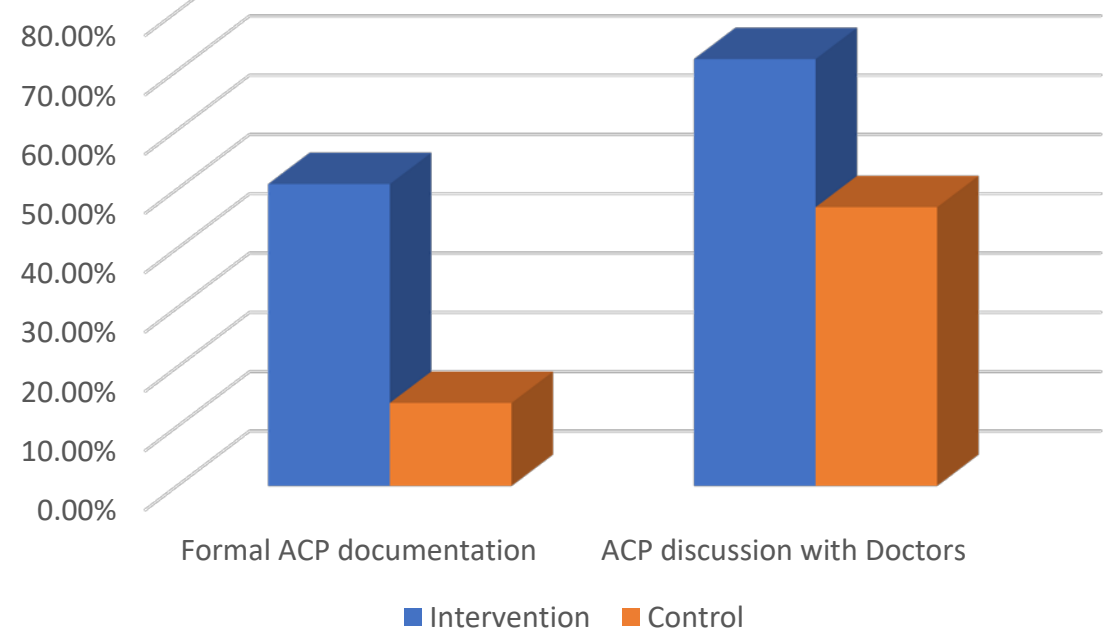
Nurse-led ACP intervention

- N = 149 (Male 63%; COPD 64%)
- **Intervention: ACP facilitation**
 - 2 senior nurses experienced in severe illness communication
- At 6 months:
 - **Higher formal ACP documents** (p<0.001)
 - 1. Completed AD or ACP form
 - 2. Written nomination of legal surrogate
 - **More ACP discussions with doctors** (p<0.005)

BMJ Open Advance care planning uptake among patients with severe lung disease: a randomised patient preference trial of a nurse-led, facilitated advance care planning intervention

Craig Sinclair,¹ Kirsten Anne Auret,¹ Sharon Frances Evans,² Fiona Williamson,¹ Siobhan Dormer,³ Anne Wilkinson,⁴ Kim Greeve,⁵ Audrey Koay,⁵ Dot Price,⁶ Fraser Brims³

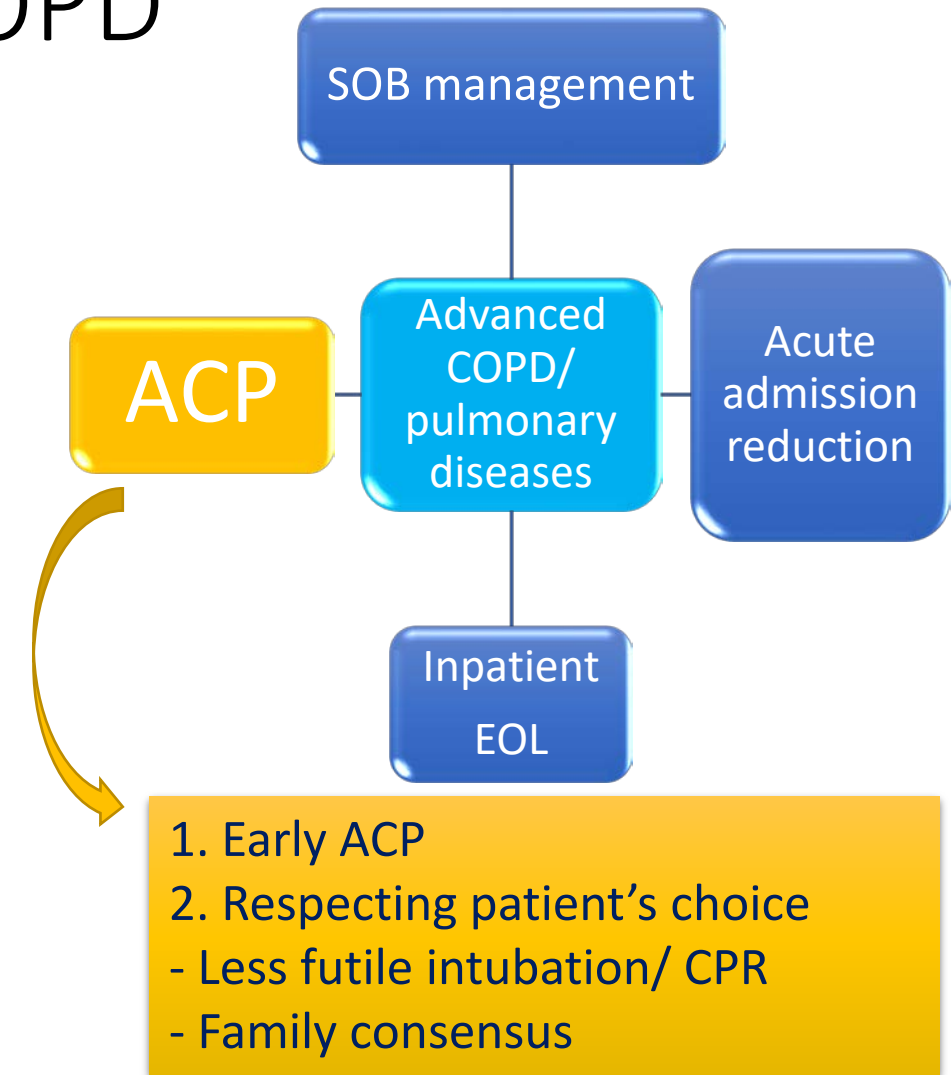
BMJ Open 2017;7:e013415. doi:10.1136/bmjopen-2016-013415



Local service for advanced COPD

靈實醫院
晚期呼吸系統疾病
紓緩治療服務

Hospital Authority Convention 2019
2019 醫院管理局研討大會



PC for advanced respiratory diseases in HHH

- Referral criteria

- 1. **Disabling dyspnea at rest**, unresponsive to bronchodilators, resulting in decreased functional capacity
- 2. **Progression** evidenced by increasing hospitalizations and/or respiratory failure
- 3. **Hypoxaemia** at rest (pO₂ <55 mmHg or oxygen saturation <88%) or **hypercapnia** (pCO₂ >50 mmHg)

NHO Medical Guidelines 1999

	HHH
Patient number	425 in 2010-2018
COPD	84%
Other non-cancer lung diseases	16%
Age (years old)	76.5 years old
Length of service (Median)	166 days (IQR 41-427 days)
Use of long term (LT) device	
1. LT oxygen therapy	82.3% ¹
2. Home Non-Invasive Ventilation (NIV)	26.7% ¹
ACP with documentation	100%¹

1. Ng JSC. HKSPM Newsletter 2012 Issue 2:19-22



Views of PC (COPD) patients on life sustaining treatments

NOT for CPR (DNACPR order)		Total: 75 deceased patients
Patient		70
- Accept		- 59 (84.2%)
- Refuse		- 3 (4.3%)
- Not sure/ Let family decide/ Let health care workers decide		- 8 (11.4%)
Family		60
- Accept		- 47 (78.3%)
- Refuse		- 1 (1.7%)
- Not sure/ Let patient decide/ Let health care workers decide		- 12 (20%)
NIV as a life sustaining treatment		Total: 75 patients
Patient		45
- Accept		- 34 (75.6%)
- Refuse		- 9 (20.0%)
- Not sure/ Let family decide/ Let health care workers decide		- 2 (4.4%)

Same preferences in mechanical intubation as in CPR in this cohort



Conclusion

- Remember the typically unpredictable disease trajectory – consider early ACP!
- Identify the triggers to initiate ACP
- Overcoming barriers:
 - Understand and engage the patients
 - Grasp the triggers!
 - Consider system implementation



ACP in advanced COPD

- 「吾」可預·計
- <https://www.youtube.com/watch?v=roy-plUlkPc>



Q&A

Thank you!

