

# Discrepancies In Provision Of End Of Life Care In Patients With Malignant And Non-Malignant Respiratory Disease

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## Abstract

### Background:

End of life (EoL) care is often suboptimal in chronic respiratory illness, compared to thoracic malignancy despite the benefits of Palliative Care.

### Objectives:

Evaluate differences in current end of life care practices between patients with malignant and non-malignant terminal respiratory illness to improve future delivery of anticipatory care planning.

### Design, setting and subjects:

Retrospective review of all Respiratory patients admitted to Royal Perth Hospital in Australia, presenting with a 'terminal admission' between 2015 and 2017, defined as patient death or discharge for terminal care to hospice/home. Patients without an underlying chronic/end stage respiratory illness were excluded. Data were collected through medical and investigation records.

### Results:

Of 89 cases, 37 had thoracic malignancy and 52 had non-malignant disease. Those with non-malignant disease were less likely to be referred to Palliative Care (8.1% vs 28.8%,  $p=0.016$ ) or have informal discussions regarding end of life wishes (73.6% vs 92.1%,  $p=0.03$ ). More of these patients died in hospital (63.5% vs 37.8%,  $p=0.017$ ), received non-invasive ventilation (48% vs 11.1%,  $p=0.001$ ) and had Palliative Care referral only on day of death (21.1% vs 2.7%,  $p=0.018$ ). Most frequent general EoL clinical indicators in both groups were deteriorating symptom burden, decreasing response to treatments and ECOG status  $\geq 3$ . In the COPD subgroup they included FEV1 < 30%, MRC Grade 4/5 dyspnoea and meeting criteria for long-term oxygen.

### Conclusions:

Significant disparity exists in provision of end of life care between these groups. The common general and disease specific end of life clinical indicators are identified, which may prompt early palliative care input and anticipatory care planning.

## INTRODUCTION

Chronic respiratory conditions impose a significant burden of disease on the community. Chronic Obstructive Pulmonary Disease (COPD) and lung cancer are the fourth and fifth leading cause of death in Australia respectively<sup>1</sup>. Involvement of palliative care services and end of life planning in patients with COPD is suboptimal compared to those with lung cancer 2-5. Early provision of palliative care

in patients with metastatic non-small-cell lung cancer has been shown to improve quality of life, mood and survival. Additional benefits included greater documentation of resuscitation preferences and less aggressive care at the end of life<sup>6</sup>. Conversely, patients with end stage COPD are more likely to undergo invasive procedures and admission to the intensive care unit (ICU), and be less likely to receive hospice care, end of life discussions and symptom control

medications compared to patients with lung cancer<sup>4,7,8</sup>. There is minimal literature on end of life management in patients with other end stage respiratory conditions such as interstitial lung disease and bronchiectasis.

In the Study to Understand Prognosis and Preferences for Outcomes and Treatments (SUPPORT)<sup>5</sup>, patients with COPD compared to patients with lung cancer were much more likely to die in the ICU, on mechanical ventilation and with dyspnoea. They were also more likely to receive intubation and cardiopulmonary resuscitation (CPR) despite preferring treatments focused on comfort rather than on prolonging life. Other studies have found that patients with COPD were more likely to receive long term home care, but were significantly less likely to receive palliative care services compared to patients with lung cancer<sup>9</sup>. These patients are therefore unable to benefit from the expertise of a multidisciplinary palliative care team despite the known high symptom burden reported in patients with end stage COPD<sup>5,8,10</sup>. It appears that health care for these patients is often initiated in response to acute exacerbations, rather than proactively based on previous discussions and plans developed for future management. In one study, only one patient had an anticipatory care plan in place despite one-third of the cohort having required non-invasive ventilation (NIV) in the preceding twelve months<sup>11</sup>.

Identifying end of life clinical indicators in patients with non-malignant terminal respiratory disease is difficult and variable. Forced expiratory volume in one second (FEV1) traditionally has been accepted as the single best predictor of mortality in COPD population studies, and is also utilised in the grading of severity of COPD<sup>12-14</sup>. The body mass index, airflow obstruction, dyspnoea and exercise capacity (BODE) index have been developed with demonstrated utility in the prediction of prognosis. General clinical criteria have also been developed to help identify patients at high risk of mortality or morbidity over the last six months of their life. One such tool that has been well validated in the acute and primary care setting is the Gold Standard Framework (GSF)<sup>15</sup>. This tool aids identification of adult patients with advanced disease in the last months/years of life, who are in need of supportive and palliative care. It has been shown to improve the quality of end of life care provided, improve the coordination, planning and communication of end of life care issues, as well as reduce hospitalisation<sup>16-24</sup>.

The aim of our research was to evaluate differences in current end of life care practices in patients with malignant

and non-malignant chronic respiratory disease admitted to Royal Perth Hospital. Collated data will be used to inform and optimise current practice, and identify the most common end of life clinical indicators that can be utilised to facilitate prompt and appropriate referral to Palliative Care. Moving forward, the aim is to develop an outpatient based pathway for anticipatory care planning in appropriate patients with end stage non-malignant respiratory illness. This would assist clinicians, patients and families in accessing timely, high quality, evidenced based end of life care as well as minimising recurrent admissions and unwanted invasive procedures in this patient group.

## **MATERIALS AND METHODS**

We conducted a retrospective review of all Respiratory patients presenting to Royal Perth Hospital with a terminal admission from January 2015 to December 2017 inclusive. A terminal admission was defined as an admission with the outcome being death in hospital, or discharge either to home or hospice for terminal care. Review of patient discharge summaries, electronic referrals, pathology and imaging systems and medical records were used to confirm eligibility for inclusion. We included patients with a chronic respiratory illness (including COPD, ILD, bronchiectasis, thoracic malignancy or a combination of these). Patients were excluded if they did not have such a diagnosis, or if the cause of death was not deemed to be related to their underlying respiratory illness.

Data collection included information on patient demographics, number of comorbidities, outcome of admission (in hospital death or transferred for terminal care), and identification of general and (where appropriate) disease specific end of life clinical indicators. Details of the terminal admission included discussion and timing of resuscitation status, number/use of invasive investigations/treatments (blood tests, CT chest, arterial blood gas, non-invasive ventilation), involvement and timing of Palliative Care input and discussion of end of life (EoL) care issues including EoL care domains. Specific domains included preferences regarding place of death/ location of end of life care, provision of life prolonging treatment, pain and symptom management, spiritual needs (such as religion) and if a proxy decision maker had been appointed. Information on the number of hospital admissions and outpatient appointments in the 12 months preceding the patient's terminal admission was also collected.

The tool used in this study for identification of general end

of life clinical indicators was the GSF discussed above 15. It was felt to be most applicable to our RPH population. Indicators include an Eastern Cooperative Group (ECOG)  $\geq 3$ , unstable and/or deteriorating symptom burden, decreasing response to treatments, more than 10% weight loss in the last 6 months, serum albumin  $< 25\text{g/L}$  and repeated unplanned admissions with a primary respiratory diagnosis. Disease specific end of life indicators were only identified for the COPD population, and also taken from the GSF. These included a FEV1  $< 30\%$ , recurrent admissions for COPD exacerbations, meeting criteria for long term oxygen therapy, Medical Research Council Grade 4/5 dyspnoea, right heart failure,  $> 6$  weeks of total steroid therapy in the preceding 6 months and respiratory failure requiring NIV/ICU/HDU admission)<sup>15</sup>.

The primary end point was the difference in uptake and timing of Palliative Care between the two groups, defined as the proportion of patients being referred to Palliative Care and the time point at which they had been referred (prior to admission, on presentation, terminal phase of illness (when active treatment was withdrawn) or on day of death). Descriptive statistics and Past 3 statistical software package for Chi-squared and t-tests were used for comparison between groups. Approval for this study was provided by the East Metropolitan Health Service Research and Governance Unit.

## RESULTS

89 patients were eligible for inclusion, of which 52 had a chronic respiratory disease and 37 had thoracic malignancy (see Figure 1).

Patient demographics and comorbidities are described in table 1. The mean age was similar between the two groups. Of the group with chronic respiratory disease, the most common respiratory condition was COPD (63.5%). The majority of patients in both groups had between 5-10 comorbidities.

Patients with chronic respiratory disease were less likely to be referred to Palliative Care overall compared to those with thoracic malignancy, and more likely to be referred on day of death (see Table 2). The majority of patients in both groups were referred to Palliative Care in the terminal phase (when active management was withdrawn). More patients with chronic respiratory disease died in hospital (63.5% vs 37.8%,  $p=0.17$ ) rather than being transferred back home or to hospice for end of life care.

Only 5.6% of the entire cohort had documentation of formal discussions of end of life care; 3 had an Advanced Health Care Directive, 2 had an Enduring Power of Guardianship. Patients with thoracic malignancy were more likely to have informal discussions regarding end of life wishes during admission (92.1% vs 73.6%,  $p = 0.03$ ). More end of life care domains were discussed when Palliative Care were involved in the patients management ( $3.7 \pm 1.8$  vs  $0.6 \pm 1.0$ ,  $p = 0.0001$ ).

The most common general end of life clinical indicators present in the entire patient population studied included an unstable and/or deteriorating symptom burden, decreasing response to treatments, and ECOG $\geq 3$ . The most common COPD specific end of life clinical indicators identified were MRC Grade 4/5 dyspnoea, meeting criteria for LTOT and a FEV1  $< 30\%$  (see Table 3).

Patients with chronic respiratory disease were more likely to be prescribed NIV (48% vs 11.1%,  $p = 0.001$ ) and have more ABGs performed (mean number of tests  $5.7 \pm 6.4$  vs  $2.2 \pm 1.8$ ,  $p = 0.0001$ ). There was no significant difference between the mean number of other investigations (blood tests, imaging studies), MET calls or number of patients receiving ICU level care between the 2 groups.

When resuscitation decisions had not been discussed prior to the terminal admission, more patients with thoracic malignancy had goals of patient care discussions on presentation compared with the non-malignant group (56.8% vs 28.8%,  $p = 0.001$ ). (see Table 4).

In the 12 months before presentation to hospital, patients in the chronic respiratory disease group had a mean of  $4 \pm 2.9$  hospital admissions with a mean total length of stay of  $21.9 \pm 20.8$  days, and an average of  $4 \pm 2.8$  Respiratory outpatient clinic appointments.

**Table 1**

Baseline patient characteristics, according to study group

	Chronic respiratory disease, n (%)	Thoracic malignancy, n (%)
No of cases	52 (58.4%)	37 (41.6%)
Mean age, years (SD)	71.5 (11.6)	73.9 (8.9)
Male	33 (63.5%)	24 (64.9%)
< 5 comorbidities	12 (23.1%)	15 (40.5%)
5-10 comorbidities	36 (69.2%)	19 (51.4%)
> 10 comorbidities	4 (7.7%)	3 (8.1%)
<b>Underlying condition</b>		
COPD	33 (63.5%)	†
ILD	10 (19.2%)	†
Bronchiectasis	5 (9.6%)	†
Other	4 (7.7%)	†

**Table 2**

Timing and uptake of Palliative Care between patients with chronic respiratory disease and thoracic malignancy

Palliative Care input	Chronic respiratory disease, n (%)	Thoracic malignancy, n (%)	p value
None (Not referred)	15 (28.8%)	3 (8.1%)	0.016
Prior to terminal admission	8 (15.4%)	2 (5.4%)	NS†
On presentation	1 (1.9%)	6 (16.2%)	0.01
In terminal phase	28 (53.8%)	26 (70.3%)	NS†
On day of death	8 (21.6%)	1 (2.9%)	0.018

† not significant

**Table 3**

Most frequent general and COPD specific end of life clinical indicators

General EOLC indicator (entire cohort)	n (%)
Unstable and/or deteriorating symptom burden	72 (80.9%)
Decreasing response to treatments	55 (61.8%)
ECOG 3 or more	51 (57.3%)
<b>COPD specific EOLC indicator (COPD cohort only)</b>	
Dyspnoea MRC Grade 4/5	25 (75.8%)
LTOT criteria	21 (63.6%)
FEV1 < 30%	21 (63.6%)

**Table 4**

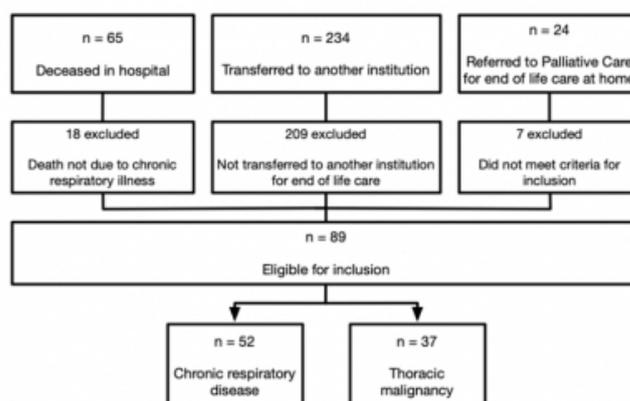
Timing of resuscitation decisions between patients with chronic respiratory disease and thoracic malignancy

Timing of discussion	Chronic respiratory disease, n (%)	Thoracic malignancy, n (%)	p value
On presentation	15 (28.8%)	21 (56.8%)	0.001
During terminal phase	16 (30.8%)	7 (18.9%)	NS†
No record of documentation	1 (1.9%)	4 (10.8%)	NS†

† not significant

**Figure 1**

Patient selection for inclusion



**DISCUSSION**

We found significant disparity in the uptake of Palliative Care and provision of end of life care in patients with chronic respiratory disease compared to those with thoracic

malignancy.<sup>2-5</sup> More patients with end stage chronic respiratory disease died in hospital, and fewer of these patients who could have potentially benefited from the expertise of the Palliative Care team were referred. The higher rate of in-hospital death in the non-malignant group is almost certainly multifactorial. The utilisation of life prolonging treatments like NIV was significantly higher in this group. The decision to palliate was also made later, often on the day of death. This leaves little/no time for discharge planning, even if the patient's wish is to die at home. Specialty teams often have difficulty navigating the requirements for discharge of a terminally ill patient to home or hospice, and the increased referral rate to Palliative Care in the thoracic malignancy group, along with the earlier time point of referral, likely facilitated appropriate planning and increased discharge for terminal care.

The reason patients with chronic respiratory disease received more aggressive intervention during their terminal admission needs to be considered. This may have been because of a lack of, or limited discussions being had regarding the patient's wishes surrounding life prolonging measures and other end of life care domains, prior to the terminal admission. We found that patients with chronic respiratory disease had fewer discussions regarding resuscitation and goals of care on presentation compared to those with thoracic malignancy. This perhaps reflects the differences in clinician perceptions of disease trajectory or the acuity of presentations with an acute deterioration. Similarly, there may have been limited or no consideration given to a patient's prognosis outside of the acute admission. Furthermore, the reduced uptake of Palliative Care services may also have contributed to unnecessary and arguably futile investigations and management for these patients.

Predicting prognosis in chronic respiratory conditions, particularly COPD, is notoriously difficult. In our cohort of COPD patients, 4 patients died more than 100 days after referral to palliative care in what was thought to be the terminal phase of life. There is a lack of validated prediction models that estimate survival in patients with chronic respiratory conditions such as COPD. Furthermore, the heterogeneity of disease, patient population, disease burden and patient trajectories means that prediction of short-term prognosis is extremely challenging<sup>2</sup>. This compounds the difficulty in predicting the ideal timing of advanced care planning, as ideally this would be initiated in the outpatient setting when clinically stable. However, in practice most end

of life discussions are initiated when patients are unwell and hospitalised<sup>25</sup>.

It is important to consider whether opportunities for earlier intervention and initiation of end of life care discussions in patients with chronic end stage respiratory disease exist, to minimise unwanted and distressing interventions. Identifying appropriate patients with whom to engage in these discussions is the first important step. Literature indicates there are 3 important triggers to consider; one of them being the presence of end of life clinical indicators. In this study, we have identified the most common general and disease specific clinical indicators present in patients with non-malignant respiratory disease, specifically those with COPD. These indicators are easily recognisable and a useful way of identifying patients who may benefit from early Palliative Care referral to facilitate commencement of advanced care planning (ACP). An additional clinical trigger not assessed in this study due to its retrospective nature, is "The Surprise Question" – would you be surprised if this patient were to die in the next few months, weeks or days?. The third aspect is patient choice or need; the patient with advanced disease makes a choice for comfort care only, or is in special need of supportive/palliative care. Combined, these three triggers provide a robust and validated framework for early identification of the patient potentially nearing end of life. Assessing the number of hospital admissions and outpatient appointments prior to the patients' terminal admission is one way of addressing whether opportunities exist for appropriate advanced care planning discussions. We have identified that such opportunities are present, given the number of hospital attendances patients with chronic respiratory disease had in the 12 months preceding their death.

The final discussion point arising from our findings is the overall very low numbers of formal advanced care planning in both groups (5.6% of the entire study population).

Similarly, we found that Palliative Care in general was an underutilised resource. The most common time to refer any patient to an end of life care specialist was at a time when active management was withdrawn, even in those with malignant disease. Many patients with chronic respiratory disease were referred only when death was imminent or on the day of death itself. We found that specialist Palliative Care input ensures more comprehensive end of life care discussions and assists in facilitating the wishes of patient and family. Those referred too late, or not at all, are denied

this opportunity.

We hope to build on the findings of this study and develop a multidisciplinary outpatient service for appropriate patients with end stage non-malignant respiratory disease to provide early introduction of Palliative Care services and facilitate advanced care planning. A requirement of the service would be to ensure sufficient time for assessment and discussion, to support patients, caregivers and clinicians along the end of life care journey. This is often difficult to do in busy, overbooked outpatient clinics or 'on the run' during a ward round. Sinclair et al recently assessed whether a nurse led ACP intervention (in the clinic or home setting) increased uptake of ACP in patients with advanced respiratory disease in 149 patients with respiratory malignancy, COPD or ILD. They found this an effective intervention, particularly among those already with a preference to engage in ACP, those that attended multiple sessions or involved a family member or carer in the discussion<sup>26</sup>. The latter would be important considerations in planning such a service.

Our study has some limitations. The relatively small sample size and single centre experience may mean the results demonstrated do not translate readily across different centres and patient populations. We also relied on the accuracy and completeness of documentation and paper records. Missing or unobtainable records may have underestimated the degree of advanced care planning in our population.

## CONCLUSION

We have demonstrated significant disparity in the provision of end of life care between patients admitted to Royal Perth Hospital with chronic respiratory conditions and thoracic malignancy. We feel that opportunities exist to allow clinicians to open the discussion regarding end of life care, explore patient and caregiver preferences and prompt thought regarding advanced care planning. There exist common and readily assessable clinical indicators which can be utilised in practice to identify appropriate patients for such discussions early, so that they have an opportunity to engage and express their wishes before a terminal event renders them unable to do so.

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