



CASE BASED DISCUSSIONS

COPD, end of life and Ceiling of Treatment

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CASE HISTORY

An elderly patient with severe COPD and at least four previous admissions with acute on chronic respiratory failure was admitted under my care. During the final admission, an end-of-life conversation took place with the patient and his family, acknowledging that the patient was terminally ill. It was agreed that treatment would be limited to oxygen, fluids, lorazepam and morphine. This was documented, but at 3:00 next morning, when nursing staff noted the patient to be more breathless, the on-call registrar commenced non-invasive ventilation (NIV). The patient died 4 h later, incommunicado. The family lodged an informal complaint.

DISCUSSION

Death is inevitable. Death is sometimes preventable, but ultimately it is only postponed. This existential truth applies to us all. More immediately, the logic applies to patients with severe COPD just as it does to patients with disseminated malignancy. The only difference between these situations is that the trajectory towards end of life is less predictable in COPD; the distinction between preventable and inevitable death is more difficult to make. However in 'frequent flyers' with severe COPD, the distinction is crucial in deciding how to provide best possible care. Just because it is difficult does not mean that the challenge should be avoided. How we manage life-threatening exacerbations of COPD should be *appropriate* and we need to be prepared to adapt our approach as the patient nears the end of life. Such responsiveness will impact positively on the quality of care received by patients and perceived by families.

Many studies have highlighted the predictors for mortality for COPD. The underlying assumption is that by identifying these factors, we will focus our efforts on high-risk patients with a view to reducing mortality. The most reliable predictor of mortality is the frequency of exacerbations, and the most reliable predictor of exacerbations is the frequency of exacerbations in the recent past.¹ These facts tell us that patients experiencing repeated exacerbations are already on an end-of-life trajectory. Leaves that turn yellow or red in autumn are already on the way to falling to the ground.

Despite this evidence, the fact that death is the likely outcome in frequent flyers does not often guide patient management. The same treatment protocols are applied on a 'one size fits all' basis. In the stressed and urgent circumstances that operate in emergency departments and medical receiving units, and especially if the doctor is meeting the patient for the first time, the diagnosis of dying is

often in the 'too hard' basket. There is also a fear that by stepping back from applying maximum possible treatment, junior doctors will be exposed to criticism and censure. The default position is to intervene first and ask questions later. But is this best practice? Is it ethical? This risk-averse approach is a powerful incentive to ignore the possibility that limited but supportive care may be best.

The possibility that patients with severe COPD (or any other end-stage organ failure) are at the end of life does not occupy the minds of those for whom hospital mortality is the metric for judging quality of care. The folly of this thinking has been highlighted² but is often ignored by service and risk managers, NHS executives and politicians whose greatest fear is the undiscerning media. As has been pointed out in *Thorax*, unless inevitable deaths are distinguished from potentially preventable deaths, mortality data are open to misinterpretation.³ The consequences include that the blame game is upregulated and pressures on front-line staff are intensified. Staff and patients alike are trapped in the treadmill of 'fix it' medicine despite all the evidence that maximal medical therapy will be futile.

My own journey into this realm involved the typical case of end-stage COPD outlined above. Apart from being understandably distressed by the death of their father, the family's grief was compounded because the dignity of his death was compromised. The contradictory behaviour of our staff and the isolation conferred upon him by NIV were upsetting and prompted them to vent their anger on me. I resolved that such an event would never happen again.

Our failures were not about whether team members cared about the patient: they did. Nor were they about the methods used to treat worsening COPD: guidelines were followed. Our failures centred on *inadequate communication leading to discontinuity and inappropriateness of care*. First, although the patient's notes documented that an end-of-life conversation took place, and that palliative treatments were to be given, they did not include the fact that certain treatments were NOT to be given, including NIV. (Occasionally NIV is given palliatively and is acceptable to patients as such, but this was not the case here.) Similarly, the hand over to night staff did not include what was NOT to be done. Third, in the absence of this negative but nonetheless specific information, the default position for the junior doctor, unfamiliar with the patient, was to 'go by the book'. This resulted in interventions which were *futile, burdensome and contrary to the patient's and family wishes*.



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Table 1 Page 1 of the Ceiling of Treatment document being piloted by NHS Lanarkshire

**CEILING OF TREATMENT /
RESUSCITATION PREFERENCES****FOR PATIENTS WITH IRREVERSIBLE
CHRONIC RESPIRATORY FAILURE,
MALIGNANCY, AND / OR
MULTIPLE CO-MORBIDITIES**

Name.....

CHI number

Patient assessment and treatment

Ceiling of Treatment needs to be established when there is an acute on chronic deterioration in the patient's principal condition (COPD, lung cancer, ILD) where the patient is known to be at the end of life, especially if the acute event is itself life threatening or has the potential to become a terminal event. Refer to Anticipatory Care Plan where this is available.

Assuming that other immediately reversible problems have been addressed (e.g. pneumothorax), management of the patient's acute respiratory distress **SHOULD ALWAYS INCLUDE SYMPTOM RELIEF** e.g. low flow oxygen, opiates, haloperidol, benzodiazepine.

Thereafter, the patient's ACUTE MANAGEMENT **MAY INCLUDE THE FOLLOWING:** (Circle YES or NO. Changes can be made at any time later if necessary).

ARTERIAL BLOOD GAS ANALYSIS	YES / NO
ANTIBIOTICS	YES / NO
PREDNISOLONE	YES / NO
NON-INVASIVE VENTILATION (BiPAP)	YES / NO
TRANSFER TO HIGH DEPENDENCY UNIT	YES / NO
ICU / POSSIBLE MECHANICAL VENTILATION	YES / NO
CPR IN THE EVENT OF CARDIO-RESPIRATORY ARREST	YES / NO

Active consideration should be given to the need for spiritual care. This document should be used in conjunction with the National Guideline for Palliative Care in the Last Days of Life.

Person completing this document:

..... (signature) (name in capitals)

..... (position) (date) (time)

This has been discussed with the patient / the patient's family or other designated support person, or obtained from a previously written Ceiling of Treatment or ACP YES / NO

Authorised by: (consultant)(date)

See over for guidance notes

These are key words. Although this was technically a systems error, the underlying paradigm needed to be changed. Our immediate practical response was to pilot the concept of Ceiling

of Treatment. A pro forma was developed, and attached at the front of patients' notes, summarising interventions which, against the background of an end-of-life trajectory, are

Box 1 Page 2 of the Ceiling of Treatment document being piloted by NHS Lanarkshire

Guidance notes

1. The Ceiling of Treatment document should be used in the event of an admission to XX Hospital under the care of a Respiratory Medicine consultant. Its provisions will be guided by the consultant. It will be used when there is an acute on chronic deterioration in the patient's principal condition, usually COPD, lung cancer or interstitial lung disease, especially if the illness trajectory is one of steady decline despite optimal medical management, and/ or the acute presentation has the potential to become a terminal event.
2. Ceiling of Treatment is not a binding advanced directive, but is designed to provide good communication about, as well as appropriate limitations to, interventions which are likely to be burdensome, futile or contrary to the patient's wishes.
3. The provisions in this document will, where at all possible, have been discussed and agreed with the patient, their family, Power of Attorney or designated next of kin. They may already have been documented in an Anticipatory Care Plan (ACP).
4. Ceiling of Treatment requires to be confirmed in writing (signature) and/or updated by the relevant consultant or staff grade specialist (Drs AA, BB, CC) within 24 h of admission.
5. Standard do-not-attempt-cardiopulmonary-resuscitation orders must still be used in addition to Ceiling of Treatment. This document is not a replacement, even although reference to CPR is made in this document.
6. The Ceiling of Treatment document applies only to the CURRENT admission up till the date of discharge and thereafter it ceases to apply. At the time of any subsequent admission, a new Ceiling of Treatment form should be drawn up and inserted into the patient's notes. The old one should have the words OBSOLETE written across it in block capitals, with the date and initials.
7. The Ceiling of Treatment document should be updated with reference to the previous Ceiling of Treatment document or Anticipatory Care Plan at each subsequent admission.
8. The existence of a Ceiling of Treatment and its current provisions should be referred to in the patient's discharge summary.

considered *futile, burdensome and contrary to the patient's wishes*. The idea is not original. It is well established in the form of do-not-attempt-cardiopulmonary-resuscitation (DNACPR) orders. DNACPR is essentially the final step in a Ceiling of Treatment ladder. The pro forma currently being piloted by NHS Lanarkshire is shown in table 1 and box 1. After many iterations, we have found that a generic version is inadequate, and that disease-specific versions are required not just for patients with respiratory failure, but for cardiac, renal and hepatic failure and malignancy.

Several aspects to Ceiling of Treatment need to be highlighted. First, it is primarily a communication tool for use in hospitals and not an advance directive. Ideally, it should be informed by an existing Anticipatory Care Plan (ACP),⁴ but its scope is much more limited. It is particularly useful for staff

faced with patients whose early warning score (EWS) signals deterioration (eg, Rapid response teams). It permits a different response depending on whether a change in the EWS signals a preventable death or one which is anticipated and inevitable. Similarly, if a patient is being transferred as a 'step-down' or 'step-up' to another medical unit, Ceiling of Treatment familiarises staff with important information and provides them with security in future clinical decision making.

Ceiling of Treatment is consultant-led or at a minimum, consultant-endorsed. It prompts and ensures an end-of-life discussion with the patient and their family where at all possible. It emphasises that reversible causes of deterioration should be addressed, and that *all* patients should receive symptom relief. It assumes that all current treatments will be continued and that treatment will be escalated to the highest level unless specifically proscribed. It does not provide for the withdrawal of any treatment. This may be a reasonable thing to consider, but is not the objective under the term 'Ceiling of Treatment'. Finally, the contents apply only to a current admission and require to be updated at subsequent admissions. The end-of-life choices by a patient with COPD often change with time, especially if overall quality of life is deteriorating, and the interval between admissions is becoming shorter. All of these features are recommended in the recent report 'More Care, Less Pathway'.⁵

Whatever its weaknesses, the Liverpool Care Pathway (LCP) provided a valuable tool to support best possible care for many terminally ill patients: "when the LCP is used properly, patients die a peaceful and dignified death".⁵ However, with the planned phasing out of the LCP, there is an urgent need to strengthen our protocols for the management of patients who are at the end of life. Ceiling of Treatment fits into this approach not as a stand-alone entity, but as a component part. The principles are not just relevant to patients who are terminally ill, but extend more widely. There is growing evidence that limiting medical interventions contributes to improved quality of overall care, including the quality of death.

This piece is written as a vehicle for sharing an idea because the issues are topical and timely. At the time of writing, the Ceiling of Treatment project in NHS Lanarkshire is in its earliest development, and we have not yet evaluated the effectiveness of this particular model. However anecdotally, nursing staff in particular benefit from the security that, when responding to a sick patient's needs, *futile, burdensome interventions* can be avoided.

That death is inevitable in a significant proportion of patients with COPD may be discouraging. However, we owe it to them to ensure that by acknowledging the reality, the quality of their death, however distressing, is not made worse by futile efforts to save their lives.

Competing interests None.

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