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### Improving quality of care for end-stage respiratory disease: changes in attitude, changes in service

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# Improving quality of care for end-stage respiratory disease: Changes in attitude, changes in service

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## Abstract

The illness trajectory for many patients with severe respiratory disease is characterized by steady decline. Yet most healthcare resources are poured into managing acute exacerbations that are only temporarily effective. Further, ‘bad deaths’ can result from inappropriate medical interventions at times of crisis. In this article, we describe a range of changes in attitudes, behaviour and service provision that together focus on improving quality of care for respiratory patients with frequent crises. These changes include prognostic conversations, developing and implementing anticipatory care plans both in hospital and in the outpatient settings, and establishing a supportive care clinic devoted to complex disease and optimizing palliative care. The underpinning philosophy is that common sense and compassion should motivate broader and more flexible care much more than adherence to the ‘curative–restorative’ guidelines-based model.

## Keywords

COPD, acute exacerbations, palliative care, advance care plan, treatment escalation/limitation, care bundle

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## Introduction

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality in most Western countries. In the United Kingdom, 5.3% of all deaths in 2012 were attributed to COPD as the primary cause.<sup>1</sup>

The trajectory of physical decline for patients with COPD is very variable (see Figure 1).<sup>2</sup> It includes partially reversible episodes of decompensation against a background of irreversible deterioration in respiratory health. A range of comorbidities increase the risk of death during acute exacerbations, but the risk factors for mortality in the long-term are different.<sup>3</sup> There are no reliable physiological markers that predict survival in individual patients. Only exacerbation frequency has prognostic significance. Once a patient has had two or more acute exacerbations of COPD (AECOPD), the likelihood of accelerated decline and death is significantly increased.<sup>4</sup> In one

study, the risk of mortality after the first exacerbation requiring noninvasive ventilatory support was 28% at 1 year, 48% at 2 years and 74% at 5 years.<sup>5</sup>

These data have underpinned the emphasis that researchers and clinicians place on interventions designed to reduce the frequency and severity of AECOPDs and, it is assumed, mortality. Yet the impact of most therapies is limited: only pulmonary rehabilitation appears to have a significant benefit on

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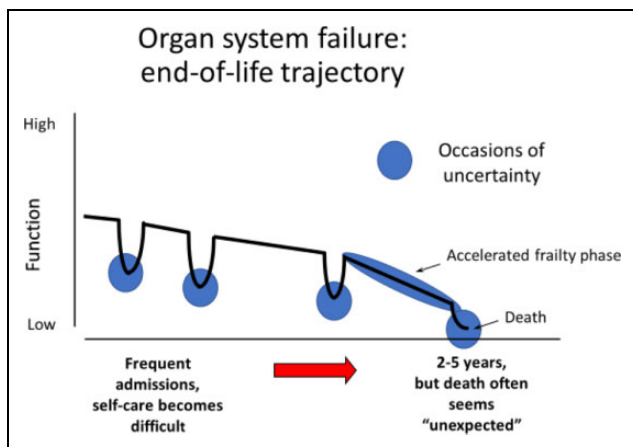
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**Figure 1.** A stylized model depicting the end-of-life trajectory for a proportion of patients with COPD. Uncertainty at the time of acute exacerbations often drives an emphasis on achieving short-term goals while neglecting the overall trend. Adapted from Murray et al.<sup>2</sup> COPD: chronic obstructive pulmonary disease.

exacerbation frequency,<sup>6</sup> but whether it reduces mortality is unknown.

What these data have not done is to shift the emphasis of treatment towards palliative and supportive care despite the World Health Organization recommendation that these should be integrated into the care of all life-limiting conditions.<sup>7</sup> The majority of patients with severe COPD experience refractory symptoms as well as psychological and spiritual stresses that result in needs that are poorly met. This is reflected in the fact that there are no substantial studies that have examined the benefits of holistic interventions in COPD.<sup>8</sup> It is also reflected in the fact that services for COPD are often less accessible than for patients with lung cancer.

Why is it that care for patients with end-stage COPD is suboptimal? The obstacles are multiple. There is failure by both clinicians and patients to recognize that COPD is a potentially life-limiting condition. Further, most clinicians (but only a minority of patients) are reluctant to engage in prognostic conversations, often because of uncertainty.<sup>9,10</sup> In turn, this leads to a neglect of anticipatory (advance) care planning (ACP) and of early palliative care.<sup>11,12</sup> The same reluctance goes hand in hand with thinking that the primary goal of treatment should be curative–restorative, especially when treating AECOPDs. This is despite the fact that the gains are limited and ‘intention-to-cure’ often conflicts with the values and preferences that most patients express during the last year of life.<sup>13</sup>

## Systemic failures

These failings have been identified for some time, and yet overall, little has changed in service provision for COPD patients. Our personal view is that the problem is greater than the attitudes and behaviours of individual clinicians. It is that in addition, clinicians function, often complicitly, within a healthcare system that is still shaped by the pre-eminence of the ‘fix-it’ paradigm.

These issues were brought into sharp focus for one of the present authors (DRT) when a 78-year-old patient with end-stage COPD was admitted under his care with a further AECOPD that was recognized as a terminal event. In spite of a relevant end-of-life conversation and optimizing palliative treatments, when the patient became more distressed during the night, the on-call staff responded by obtaining three arterial blood gas samples, setting up an aminophylline infusion and commencing noninvasive ventilation. He had previously refused this treatment. He died 3 hours later. Thus, the admission concluded with a ‘bad death’ and a complaint was lodged by his family.<sup>14</sup>

In the subsequent enquiry, several major issues were highlighted. Firstly, although an end-of-life conversation and desired palliative treatments were adequately documented and given, what was NOT documented was what ought NOT to be done. Secondly, and for this very reason, the doctor involved was unclear about what to do. He therefore adhered to the protocol for managing acute respiratory failure even though this was an entirely inappropriate decision.

Later, a hospital-wide mortality audit (not limited to respiratory deaths) revealed that this pattern of events was occurring not infrequently, that is, protocols for managing acute medical crises were being followed without regard to the context in which care was being delivered. Often interventions were *futile*, *burdensome* and *contrary to the patient’s wishes*. This picture is well described for cardiopulmonary resuscitation (CPR) and for admissions to intensive care unit, but the problem is more widespread.<sup>15</sup>

Overtreatment with curative–restorative treatments and undertreatment with palliative measures were systemic, leading to harm in patients whose vulnerability was greatest. Only rarely was there carelessness or incompetence on the part of individual doctors or nurses. The adverse outcomes were driven by a complex mix comprising the absence of timely decision-making and communication about prognosis

**Table 1.** Examples of starting-point questions for prognostic conversations.<sup>a</sup>


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'John, things seem to have changed for you over the last few months . . . have you noticed that?'

'Mary, given all that's been happening to you lately, what are your thoughts about the future?'

'I think we can get you well again this time (severe AECOPD), but have you thought much about what you might like us to do for you further down the track?'

'John, do you worry about the way things have been heading?'

'Mary, can you tell me a little bit about what you are frightened of.'

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AECOPD: acute exacerbation of chronic obstructive pulmonary disease.

<sup>a</sup>The aim is to help patients to reflect on trends and events in the recent past and to use that reflection as the basis for considering the likely future course of their health. Establishing appropriate goals of care and treatment can emerge from this approach.

and treatment preferences; discontinuity of care and the inexperience of on-call staff; adherence to treatment protocols as the default response to crises (including a rising Early Warning Score); and fear of censure if intervention was not implemented.

In response, we undertook a radical review of our approach to managing hospitalized patients with acute exacerbation on chronic respiratory disease (COPD, pulmonary fibrosis and some cases of lung cancer). In the following sections, we describe some of the measures that we adopted. No single entity has unique merits. We recognize that many of them are now being widely adopted and so we make no claims to having special expertise.

## Diagnosing dying and prognostic conversations

The most important step towards improving care is to take prognosis seriously – by which we do not mean addressing the question 'how long have I got?' but rather holding a much broader conversation with patients about the likely course of events (Table 1). William Osler said that '*Medicine is a science of uncertainty and an art of probability*'. This statement implies that managing rather than avoiding the uncertainty of a patient's condition is integral to good care. Gawande has observed that patients need doctors who are willing to have the hard discussions and help them prepare for what is to come.<sup>16</sup>

There is a key reason for making such discussions normative.<sup>17</sup> Firstly, it is *a patient's right to know* and

it is a clinician's ethical responsibility to communicate information and honest opinion *about what might lie ahead*. However much uncertainty there may be, we ought not to hide behind it but share the uncertainty with patients and their carers. Taking account of what the future may hold – often based on recent trends and events – creates a perspective that will almost always shape treatment goals. Things go always better with planning and that is only possible when the illness trajectory is taken realistically into account.

In our multidisciplinary team (MDT), we have sought to normalize thinking ahead by frequent use of the surprise question: 'Would you be surprised if this patient were to die in the next 6–12 months?'.<sup>18</sup> The question encourages intuitive integration of information about disease state, comorbidities, and social and psychological factors in order to consider whether the patient may be nearing the end of life. The surprise question has not been validated as a prognostic tool for patients with lung disease but rather is a general indicator of downward trends.<sup>19</sup>

It soon became apparent that even when prognosis is considered in planning patient care, discussing its implications with patients and relatives is challenging. Staff reluctance to do so is based on subjective inadequacies in communication skills, the death taboo, difficulties in processing uncertainty, the challenges in explaining the technical complexities of treatment while promoting shared decision-making and dealing with family members. We have therefore begun a programme that integrates the topics of discussing dying and having prognostic conversations into skills training at all staff levels and have developed appropriate educational aides.<sup>20</sup>

## The supportive care clinic

We also identified that a major factor affecting clinician's willingness to hold prognostic conversations is time and timing.<sup>21</sup> There are broadly two types of anticipatory conversation. The shorter version takes place at the time of an acute admission for AECOPD and focuses on interventions and likely outcomes that are relevant for the next few hours/days. The second focuses on longer term management and includes broader ACP. Dealing with these issues during a hospital admission can be difficult. Even if time is available, the patient may not be ready for the conversation.

To deal with this, we set up a Supportive Care Clinic. The criteria for referral were (a) the patient was admitted on two or more occasions with AECOPD and (b) the answer to the surprise question was ‘No, I would not be surprised if . . .’, as judged at a MDT meeting. The clinics were led by a consultant respiratory physician and a respiratory nurse specialist. Clinic appointments were for 45 minutes. Family members were invited. In addition to providing adequate time for prognostic conversations and the mapping of an ACP, the scope included optimizing palliative treatment of dyspnoea, addressing anxiety and depression, assessing pulmonary rehabilitation and/or long-term oxygen, managing cor pulmonale and considering long-term antibiotics and nutrition. A similar approach has been outlined in more detail by Steiner et al.<sup>22</sup> Hospital managers insisted that this endeavour had to be contained within existing clinic times and budgets. Given our commitment to prioritize care for patients at the end of life, we therefore reduced ‘routine’ COPD appointments by modifying the referral criteria for less severe disease.

The Supportive Care Clinic sought to provide a so-called care bundle that was shaped by the patient’s illness trajectory. Prognostic conversations, ACP and palliative treatments are now recommended in evidence-based guidelines as an integral part of care for patients with COPD.<sup>23</sup> However, it is disappointing that none of these key elements was included among the 26 components that have been variously included in 14 studies of discharge care bundles for patients with COPD. Although implementing ‘care bundles’ significantly reduces hospital readmissions, and this is a legitimate goal, they have no impact on quality of life or mortality.<sup>24</sup> Clearly, there is a discrepancy between guidelines’ recommendations and the scope of emerging services for patients with COPD that urgently needs to be addressed.

### **Anticipatory (advance) care planning**

Integral to the work of the Supportive Care Clinic was the development of a disease-specific ACP for patients with respiratory disease. Their value in COPD is increasingly recognized.<sup>12,25</sup> Our plan (see Online Supplement 1: ‘Making Choices’) includes generic elements common to most ACPs, for example, care arrangements when dependency increases, place of death, welfare power of attorney and will and funeral arrangements. It also includes components that are specific to the management of end-stage COPD/

interstitial lung disease, for example, escalation/limitation of treatment during future AECOPDs.

However, we were obliged to learn a number of important lessons – born of the frustration and failure that is commonly experienced with ACPs.<sup>26</sup> Importantly, leading a patient and their carer through an ACP should aim to create a shared mindset. That is far more important than the completion of documentation. Indeed, a proportion of patients shy away from a written plan if this is perceived to be the chief aim. Planning how to manage future crises (transfer to hospital, noninvasive or mechanical ventilation, CPR, etc.) is important, but this has to be nested within something broader. The key issues are not narrowly clinical, and it is helpful to approach clinical issues via a set of wider questions. They encourage thinking about the ‘bucket list’, meaningful relationships, letting go versus clinging on, life after death and preparation of the soul, anticipating loss and bereavement for the next of kin (see Table 2).

### **Treatment escalation/limitation**

Finally, in response to the problems highlighted by our index case and to reduce the potential for mismanaged AECOPDs and ‘bad deaths’ in our hospital ward, we developed what is now termed a treatment escalation/ limitation plan (TELP) (but known in our locality as the Hospital ACP (see Online Supplement 2)).

TELPs are increasingly accepted as an important adjunct to managing unstable or end-of-life patients, and there is now a national initiative in the United Kingdom to introduce the concept more widely.<sup>27</sup> The historical precedent is the Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order. By extending the scope of DNACPR to include a range of disease-specific interventions, and by ensuring that a summary is readily available, the aim is to minimize harm attributable to overtreatment/undertreatment and/or discontinuity of care in unstable patients if and when further deterioration occurs. The use of a TELP complements what has already been agreed in a pre-admission ACP. Importantly, its use is not limited to those who are terminally ill and it does not provide for treatment withdrawal or an end-of-life care pathway.

Like all forms of advance planning, the successful use of a TELP is dependent on the willingness of clinicians to consider and discuss prognosis, to appropriately set aside the one-size-fits-all ‘fix it’ approach

**Table 2.** Questions and specimen answers used in 'Making Choices, an Anticipatory Care Plan for patients with chronic respiratory disease' a disease-specific ACP (see Online Supplement 1).

Question	Sample answer
If you have been experiencing deterioration in your overall condition, including your breathing, how do you think these problems are going to affect you in the future?	<i>I am concerned that I will not be able to get out of the house.</i>
When you are thinking about your future or about dying, what is it that worries you most?	<i>I think about how I might die. I worry that I am going to suffocate and it will be a struggle to breathe at the very last.</i>
Based on your view of how things are developing OR past experiences you have had, are there any treatments which you would not wish to have in the event of sudden deterioration?	<i>I get claustrophobic when they put a mask over my face. This happened when I was on NIV treatment. It made me much more anxious.</i>
Under what circumstances would you want the goal of medical care to switch from actively attempting to prolong your life to focusing on supportive/comfort care?	<i>If I get a bad pneumonia and it's definite that I am dying even despite lots of treatment, then I would be comfortable if antibiotics were stopped.</i>
Where would you prefer to spend your last few weeks or days? What would be your ideal surroundings at this time? How could this happen?	<i>I do not want to be in a noisy hospital ward. If possible, I would prefer to be at home but that depends on how my family feel. If it's available, it would be good to be admitted to the hospice.</i>
Are your goals affected by your present state of health? Are there ways in which help might be provided so that you can accomplish your goals?	<i>It is really important that I spend time with my daughter and my 2 grandchildren. I could visit them if it was possible for the oxygen concentrator to be transported to their house for a weekend.</i>
What would help you live your life better from now on?	<i>Knowing that when the end is near, I can get help easily. I live on my own.</i>
When you are nearing the end, and may not be able to speak or be understood, are there things you would like your family or friends to know?	<i>I would like my ex-husband to know that I have forgiven him. I would like my son who lives in Australia to know that I love him very much and am very proud of him.</i>

ACP: anticipatory (advance) care plan.

to managing acute medical crises especially at the end of life and to embrace shared decision-making.

There is an increasing body of evidence to support the use of TELPs. Firstly, about a third of in-hospital emergency team call-outs involve patients who are at the end of life and for whom the need for palliative care has not been previously considered.<sup>28</sup> These call-outs can result in inappropriate overtreatment. Secondly, between 30% and 40% of major medical interventions prove to be nonbeneficial when applied in the last year of life.<sup>15</sup> Thirdly, in terminal illness, there is an inverse relationship between the intensity of medical interventions and patients' quality of death as judged by their next of kin.<sup>29</sup> Fourthly, when a TELP is introduced, there is a highly significant reduction in medical harms in hospital, primarily due to avoiding inappropriate interventions.<sup>30</sup> Finally, when advance planning (TELP or ACP) is used, there is significantly greater concordance between a patient's preferences and the care that is delivered, and this is associated with a reduction in levels of anxiety and depression experienced by their family members.<sup>31</sup>

## Conclusion

No single intervention in itself improves quality of care for patients with progressive respiratory disease, especially towards the end of life. Rather a strategy is required that begins by acknowledging that present practices are ineffective or worse, are causing harm, and then embraces a range of pragmatic solutions. What we have described here includes changes not just to individual behaviour and decision-making (for example, prognostic conversations, palliative care sooner rather than later), but also to the services that are provided by the health system (for example, the supportive care clinic). There is a dynamic two-way interaction between using tools and aides to improve care quality and the culture change that is essential in order for them to be effective.

The management of life-limiting respiratory disease begins with an attitude that is realistic and compassionate and is willing to go beyond the constraints both of the curative medical model and of the present healthcare system. Where traditional disease-oriented evidence-based guidelines and clinical behaviours are

in conflict with compassion and common sense, then the latter should be given priority.

### Authors' Note

Readers may be interested to view 'A Good Death' that deals with this topic narratively. It depicts medical care during the last 14 months of the life of a patient with severe COPD. <https://vimeo.com/39258619> (free to view)

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