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# Challenges in end-of-life communication in COPD

## Educational aims

- › To raise awareness of end-of-life communication issues in COPD patients.
- › To discuss the challenge of depression and denial at the end of life in COPD.
- › To examine relevance of concepts such as death awareness, death trajectory and a good death.

## Summary

This review describes the professional healthcare literature on end-of-life communication in chronic obstructive pulmonary disease (COPD), raising the challenge of depression and denial and describing how concepts such as death awareness, dying trajectory and a good death can help support the communication needs of individuals with COPD. Communication is not only concerned with explaining and supporting treatment decisions but should also accompany the individual throughout their illness.

▶ COPD is an incurable illness and the fourth leading cause of death worldwide [1]. COPD is associated with a significant symptom burden and poor quality of life [2]. Symptoms include breathlessness, fatigue, sleep disturbances, sputum production, cough, wheezing, a high psychological burden, fear of suffocation, depression, great impairment in activities of daily living, and poor social, economic and physical function [3]. It is a progressive, fluctuating and chronic condition [4]. Management of the disease focuses on prevention, treating acute exacerbations, as well as palliative care through long-term symptom control and maximising patient independence and emotional well-being.



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## Palliative care

Providing palliative care for an individual with COPD is challenging in terms of the physical, emotional, psychological, social and spiritual experience of living with and dying from the disease. Palliative care is defined as "the active holistic care of patients with advanced progressive illness. It includes management of pain and other symptoms and provision of psychological, social and spiritual support. The goal is achievement of the best quality of life for patients and their families. Many aspects of this are applicable earlier in the course of the illness in conjunction with other treatments" [5]. There is evidence that individuals with COPD do not receive palliative care in the same way as cancer patients, despite a similar disease burden [6], and that contemporary palliative care, in the UK at least, falls into two client groups: cancer and noncancer [7].

## Communication at the end of life

Over the past decade there has been a growing awareness of the palliative care and communication needs of disease groups other than cancer patients [8, 9]. The challenge of prognostication (discussing how long individuals will live,

uncertainty, or identifying the final days or weeks of a patient's life) for patients with COPD is widely reported [10] and has been said to lead to "prognostic paralysis where clinicians prevaricate when considering end of life issues" [11]. There is also a lack of research into the specific needs of end-stage COPD patients [12] and few evidence-based recommendations on how to discuss dying, life expectancy and future symptoms for noncancer palliative care patients [13]. There have been few studies concerning the quality of patient-physician communication about end-of-life care, specifically for patients with COPD [8]. It may be defined as "an open, two-way communication in which patients are informed about the nature of their disease and treatment and are encouraged to express their anxieties and emotions" [14].

## What communication is required?

There is evidence suggesting that COPD patients desire end-of-life discussions about decision making and the meaning of the disease for them. However, there is also evidence of barriers to such discussions (table 1). What the evidence reports is that healthcare professionals need to be self-aware of their competency and confidence in

**Table 1** Required communication and barriers to communication

Authors [ref]	Comment
WENGER <i>et al.</i> [15] GOLIN <i>et al.</i> [16]	Studies of resuscitation discussions with COPD patients identified a mis-match; patients were able to make decisions about resuscitation but were unable to communicate them with physicians.
EDMONDS <i>et al.</i> [17]	Lung cancer patients were more likely to have known they were dying and for a longer period of time than the chronic lung disease patients.
GABER <i>et al.</i> [18]	Review of 100 COPD outpatients' views on discussion of resuscitation concluded that resuscitation could be discussed with patients without causing distress.
CURTIS <i>et al.</i> [8]	Review of the differences among COPD, cancer and HIV patients' perspectives on end-of-life care provision identified specific needs from COPD patients of knowing more about the disease processes, treatments, prognosis and what dying might be like.
KNAUFT <i>et al.</i> [19]	Discussion of communication with oxygen-dependent COPD individuals reports that only 32% of patients had an end-of-life discussion and describes barriers such as patients wanting to concentrate on staying alive, not being sure which doctor would continue their care and not knowing what type of care they wanted.
SHAH <i>et al.</i> [20]	Described difficulty in predicting when noncancer patients will die and fear of causing distress when raising such issues, but in discussion with 40 patients from a teaching hospital and hospice (20 with cancer, 20 with COPD, heart failure or renal disease) revealed that patients did not object to questions about end-of-life care.
YOHANNES [10]	Suggests that patients and general practitioners may be unwilling to discuss end-of-life care because of a lack of confidence and time for such discussions, uncertainty about prognosis and lack of knowledge about available care.
WHITE <i>et al.</i> [21]	Identified that, although in the intensive therapy unit setting withdrawing life support may be discussed, long-term survival (prognosis) often was not.



communicating at the end of life. The discussions may be difficult but remain important and necessary.

## Key communication principles

One of the underlying premises for good communication skills in medicine and healthcare is that it "enables physicians to improve the patient's understanding of their illnesses, improves patient adherence to treatment regimes, uses time efficiently, avoids burn-out and increases professional fulfilment" [22]. The early work by GLASER and STRAUSS [23] highlighted the importance of communication in serious illness or terminal care and helped to influence key communication tools with themes of (professional) preparation, disclosure of news and responding to the reaction. More recently, the Calgary-Cambridge framework clarified key communication skills further (table 2).

To communicate well there are common areas of facilitative behaviours, attitudes and traits, including patient-led conversations, asking open questions, focusing on and clarification of psychological aspects, empathetic statements and educated guesses as well as active listening and positive body language, which all promote the three core therapeutic attributes [25]:

- Respect: the ability to accept the patient as he or she is.

**Table 2** Calgary-Cambridge guide

<b>1. Initiating the session</b>
Establish initial rapport
Identify the reason for consultation
<b>2. Gathering information</b>
Make organisation overt
Attend to flow
<b>3. Providing structure to the consultation</b>
Explore patients' problems
<b>4. Building relationship</b>
Use appropriate nonverbal behaviour
Develop rapport
Involve the patient
<b>5. Explanation and planning</b>
Provide the correct amount of information
Aid accurate recall and understanding
Achieve a shared understanding
Share decision making
<b>6. Closing the session</b>
Forward planning
Ensure an appropriate point of closure

Adapted from [24].



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- Genuineness: the ability to be yourself in a relationship despite your professional role.
- Empathy: the ability to understand the patient's experiences and feelings accurately and to demonstrate that understanding.

These core attitudes are essential when understanding further the benefits of communicating at the end of life in COPD (table 3).

**Table 3** Benefits of end-of-life communication

Authors [ref]	Comment
WENRICH <i>et al.</i> [26]	This study of 137 terminally ill cancer and chronic illness patients' views on patient-physician communication identified key areas, including talking honestly and straightforwardly, being willing to talk about dying, giving bad news in a sensitive way, listening to patients, encouraging questions and being sensitive to timing of such discussions.
MORGAN [27]	Discussion of the patient-doctor relationships highlights the significance between the content and process of communication skills. Patients' perceptions of doctors' inadequacy in communication are noted as arising from what the doctors communicate (content) as well as how they communicate (process).
EVANS and HALLETT [28]	Highlights the importance of the role of comfort to those who are dying, "helping persons to deal with the heavy burden of death awareness by entering their world in a compassionate and a connected interpersonal relationship".
CLAYTON <i>et al.</i> [29]	Systematic review of adults with advanced progressive life-limiting illness <2 years to live, including but not restricted to: cancer, end-stage pulmonary disease, end-stage cardiac failure, and motor neurone disease; the caregivers (including bereaved relatives) of such patients; and qualified healthcare professionals. Avoidance can lead to poorer patient satisfaction and psychological morbidity. If information provision is not honest and detailed, patients may perceive that healthcare professionals are withholding potentially frightening information. Although many healthcare professionals believe introducing the topic will unnecessarily upset the patient and dispel any hope, evidence suggests that patients can engage in such discussions with minimal stress and maintain a sense of hope even when the prognosis is poor. In addition, awareness of prognosis is associated with greater satisfaction with care and lower depression levels in patients.

## Disease trajectory

COPD has a different illness and disease trajectory to cancer, commonly having multiple admissions with exacerbations particularly in the last year of life. The difference in disease trajectories and experience of the illness is important as it means that COPD individuals, families and their professional carers have to continually discuss important and complex decisions over a longer period of time.

## The challenge of depression

The increased incidence of depression in COPD was noted by GORE *et al.* [30]. Depression may influence patient choices about life-sustaining treatments, such as resuscitation and mechanical ventilation. STAPLETON *et al.* [31] raised specific questions as to the relevance of depression as an indicator for COPD individuals viewing communication interactions poorly because of their depression, or influencing their end-of-life treatment and choice preferences. They also highlighted that if depressive symptoms improve then reassessment of treatment choices should occur [31]. Communicating with the depressed COPD patient about difficult end-of-life decisions raises further challenges for the practitioner and patient in terms of assessing whether their decisions are based on clinical depression, emotional well being, how the conversations are carried out or where they are in their illness experience.

## The challenge of denial

ZIMMERMANN [32] reviewed the clinical literature of denial and palliative care and deduced several

**Table 4** Types of end-of life discussions

Living with the disease  
 Implications and consequences of treatments  
 Prognosis and preferred place of death  
 Advance directives and resuscitation  
 Uncertain of the timing of death  
 Withholding and withdrawing treatments  
 Intubation or mechanical ventilation?  
 Long-term oxygen therapy  
 Symptom control  
 Maintaining baseline respiratory function

themes within the concept of denial (table 5) leading to three main areas for consideration: 1) a psychological (temporary) coping mechanism; 2) an obstacle to good palliative care; and 3) another way to die and manage the dying process.

The challenge of denial in COPD may lie within the realms of how to know when a patient or family is using denial as a temporary and acceptable coping mechanism or as a conscious desire not to plan for the future. Some of the theories within the sociology of death and dying can help with these concepts

## The sociology of death, dying and COPD

The sociology of health, death and dying has been of increased interest to social scientists over the past few decades [33], fundamentally changing the way we think about death and dying [34]. The understanding of the social roles of doctors and patients as described by PARSONS [35] developed a whole field of research into how patients and doctors interact. This is of interest in the individual COPD patient in terms of providing information when making decisions about end-of-life issues. A COPD patient will never be able to regain their pre-diagnosis health; thus, the Parsons obligation to "get well" is not possible. As 90% of COPD patients are smokers or ex-smokers [36], they are, therefore, likely to experience the stigma associated with smoking-related illnesses. This may contribute to their disease burden [37]. Likewise, the healthcare professional who is expected to be objective and emotionally detached will be consistently challenged over a long period of time due to: the nature of the disease, the reason for diagnosis (smoking) and dying trajectory, not to mention the intensity of patients' and families' emotions as they move within the death process and experience.

**Table 5** Key denial themes

Denial as an impediment to

1. Open discussion of dying
2. Dying at home
3. Stopping futile treatments
4. Advance care planning
5. Symptom control

Adapted from [32].

## Death awareness

Death awareness (table 6) is the degree to which a person is aware of their impending death and or the extent to which their family share or deny this awareness [23]. It is relevant when considering the COPD patient's experience because of the difficulty in prognostication and frequency of acute exacerbations. GLASER and STRAUSS [23] discussed how patients and families may not know how to recognise or interpret signs of an impending death. When communicating difficult or sensitive subjects with a patient or their family, consideration of the concept of death awareness may help to place the context of the conversation between patient and healthcare professional. For example, instead of viewing the patient as "in denial" it can help to view them in "mutual pretence" or "uncertain open" awareness, and recognising that these are valid coping mechanisms. Communication can take place on many different levels including acknowledging and recognising the patients' narrative, story and feelings; information giving and assessment and action planning or just in planning ahead.

## The dying trajectory

GLASER and STRAUSS [23] also described the components of the dying trajectory including: 1) certain death at a known time; 2) certain death at an unknown time; 3) uncertain death but a known time when certainty will be established; and 4) uncertain death and an unknown time when the question will be resolved. COPD patients predominantly have a certain death at an unknown time. A COPD patient accustomed to frequent exacerbations may find it difficult to perceive (or want to perceive) a difference in their final acute exacerbation. It is known that healthcare professionals also find prognostication difficult [10, 20]. This, combined with a lack of confidence or competence in having difficult end-of-life conversations, may result in not having these conversations at all, or having only parts of the conversations that the healthcare professional or patient feels comfortable with. Currently, in the UK, only 18% of deaths occur at home [39] and 61% of COPD deaths occur in hospital [40]. The dilemma for the COPD individual is that if, as BAUMAN [41] suggests, we, as individuals, are trying to challenge death by adapting lifestyles and strategies (*e.g.* pulmonary rehabilitation programmes) to prevent death,

**Table 6** The concept of death awareness

GLASER and STRAUSS [23]	
Closed	The patient does not recognise or denies that they are dying, although everyone else knows.
Suspected	The patient suspects what others know and attempts to confirm or negate it.
Mutual pretence	Everyone knows that the patient is dying but pretends to each other they do not know.
Open	Everyone admits that death is inevitable and behaves accordingly.
TIMMERMANS [38]	
Suspended open	Where the patient and family disregard the information given to them and are in denial; this may be a temporary coping reaction.
Uncertain open	Where the patient and family overlook the negative aspects of information and hope for the best.
Active open	The family accepts the reality of the information and acts and behaves accordingly.

then the COPD individual is set up to fail. Certain death at an uncertain time is inevitable for this group of individuals. For patients and families to live with a dying trajectory of "certain death at an unknown time" poses challenges especially in terms of constructing a "good death".

## The good death

Conceptualisation of a "good death" is frequently based around hospice cancer deaths where self-awareness, individuality, symptom control and peacefulness help to define the concept [42]. Typically, a COPD patient may suffer from severe breathlessness, weight loss, cough, purulent sputum, chest pain, weakness and fatigue. In particular, patients' and families' descriptions of breathlessness challenge the definitions of a "good death". Patients with COPD are not always able to die quietly, peacefully or in their own homes. Patients may well die in the intensive care or acute hospital setting with medical technology attached to them. It is argued that the placing of death into the hospital environment away from the home setting has meant we have lost our vocabulary to speak with the dying [43]. This is a dilemma for the patient





### Educational questions

Are the following statements true or false?

1. There is evidence that patients do want to discuss issues such as resuscitation and advance planning for the end of life.
2. Denial can be an acceptable coping mechanism.
3. An awareness of the concept of death awareness can help healthcare practitioners gauge how much patients and families may want to discuss end-of-life issues.

with COPD. They may live with, but be dying from, their disease for many years. They are therefore doing both their dying and living in their homes, but may end up in hospital at the point of death. In hospital they are then subject to the organisation and rituals of a hospital death. What then defines a good death for COPD patients? COPD patients experience a physical and social failure of their bodies with associated redefinition of their roles and function, not only at the time of their death but in the months and years preceding it. Social death, "the termination of our social existence", as opposed to our biological death, "our biological cessation" [44], is of interest in considering the experience of the COPD patient. One of the fundamental principles of palliative care is Cecily Saunders' concept of total pain. Commenting on her concept, Saunders said: "You matter because you are. You matter to the last moment of your life and we will do all we can not only to help you die peacefully but to live until you die. I coined the term total pain, from my understanding that dying people have physical, spiritual, psychological, and social pain that must be treated." [45]. There is a dilemma. How will the COPD patient who fits into the social death characteristics of "cessation of the individual person as an active agent in others' lives" be able to live until they die when the time before their

death is a prolonged period of decreased physical functioning and social role failure? The COPD patient challenges the concepts of a good death on many levels.

## Conclusion

This article has looked at some of the end-of-life communication issues for a patient with COPD. The challenges of depression or denial and the relevance of the concepts of "death awareness", "death trajectory" and a "good death" are identified. Communicating with a COPD patient at the end of life is difficult and is challenging for healthcare professionals as well as for patients and their families. As professionals, we need to be much more aware of the needs of patients with COPD and the complexities that occur because of difficulties with disease trajectory and prognostication. Further high-quality research is needed in this field in order to clarify these issues and to provide evidence-based communications strategies for professionals (such as those provided by CLAYTON *et al.* [29]) to help patients achieve the best clinical and communication outcome possible. Such research will also have relevance and resonance for other non-malignant diseases such as renal, neurological and cardiac failure.

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**Suggested answers**

1. True
2. True
3. True