



Communication skills in end-stage respiratory disease: managing distressed patients and breaking bad news

Educational aims

- ▶ To improve and give structure to challenging end-of-life communication discussions.
- ▶ To examine the assessment and management of symptoms associated with end-of-life respiratory disease.
- ▶ To examine the structured frameworks for caring for patients with cancer and explore the effectiveness of their application to end-of-life respiratory disease.

Summary

This review on when, how and whether to talk with respiratory patients about dying has been developed from a recent 3-day course, entitled End of life care in respiratory disease, which was run jointly by the British Thoracic Society and the Association of Respiratory Nurse Specialists. Aimed at respiratory specialists, the purpose was to raise debate and awareness within the speciality of the skills, evidence and best practice in end-of-life care. Participants identified their learning needs as follows: dealing with anxiety, depression, emotions and breathlessness; symptom control; and navigating the social services benefit system. The course aimed to present the key clinical skills required in a workshop style for experienced respiratory practitioners. Five doctors, 19 nurse specialists and two physiotherapists attended the course, which was held over a period of 3 days 2 months apart in 2008. This article describes the skills of end-of-life care as applied to the care of people with advanced respiratory disease, and how these were explored in this short course. We hope it will help other respiratory professionals develop and extend the relevant knowledge base and communication skills in their own teams.

▶ The thrust of the course can be broken down into three broad categories: communication skills; symptom management; and organisational tools.

Communication skills. In each day of the course one of the following interpersonal communication skills was explored with participants.

- Listening for and responding to concerns from patients
- Delivering new information (breaking bad news)

- Interdisciplinary teamwork and conflict within the team

Symptom management. For most of the participants, managing end-of-life symptoms was challenging. They debated and reviewed the evidence relating to the following.

- Breathlessness
- Anxiety
- Depression

Organisational tools. The relevance of the fol-

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Participants in the End of life care
in respiratory disease course.

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E1.13, F1, I.6

Box 1 SAGE & THYME, a model for listening and responding to patient concerns

S	etting	It is important to create some privacy and find the right time to ask about emotions and concerns.
A	sk	Asking a specific question about 'how are you feeling?' or 'you seem upset, can I ask how you are coping with this illness' shows you are willing to listen.
G	ather	Make a list of the things the patient is telling you. This shows you are listening and writing them down helps you to remember so that you can reflect them back to the patient.
E	mpathy	Use silence, give the patient space, perhaps reflect back to the patient that they have a lot going on right now - it's no wonder they feel so upset.
T	alk	Ask the patient whether they have anyone they can talk to.
H	elp	Have they been helped in the past? Most people will have someone with whom they can share concerns.
Y	ou	What do you think would help? Most people can solve their own problems. As healthcare practitioners we always feel we should have the solutions.
M	e	Would you like me to do anything or help in any way? Quite often they will not, and simply giving them the opportunity to talk will have helped.
E	nd	Simply reflect, acknowledge and conclude on the interaction, emphasising the main points discussed.

lowing structured frameworks of care was assessed with respect to the needs of people with advanced respiratory disease.

- The tools of advanced care planning
- The Gold Standards Framework for community palliative care
- The Liverpool Care Pathway for the dying patient

The course was designed to make use of the expertise within the group while introducing the topics listed above. Participants brought and discussed case studies in order to initiate discussions within the context of advanced respiratory illness.

Communication skills

Much of the research relating to communication skills in end-of-life care has been developed in cancer care. Problems relate to blocking behaviours from healthcare professionals and a failure to allow patients and carers to become partners in care [1, 2]. There is evidence to suggest that the skills of hearing and responding to the concerns of patients have become secondary to biomedical questioning and decision making

[3]. This imbalance is addressed in training modules through structured and sequential consultation skills for health professionals. The Calgary-Cambridge models for medical consultations [3] and the SPIKES (Setting up, Perception, Invitation, Knowledge, Emotions, Strategy and Summary) model for breaking bad news [4] are examples of consultation guides that integrate the patient agenda with biomedical issues.

The first communication skill practised related to the art of listening to the patient's agenda without interrupting or directing. While this is a seemingly elementary skill to teach experienced specialists, participants welcomed the structure and the guidance provided by the model used (SAGE & THYME; box 1).

Each of the nine steps of the model is based upon published evidence and guides the health professional to listen, connect with the patient's concerns and identify both the patient's support structure, as well as their own ideas and priorities. In early stage or acute stages of respiratory care, it is perhaps appropriate for biomedical questioning to be the highest priority. In advanced disease, however, different skills apply. The priorities and concerns of the individual patient begin

Box 2 The SPIKES protocol for breaking bad news

S etting	No distractions – right patient – introduce yourself – sit at the right angle and right height – get the setting right.
P erception	What is the patient's perception of why you are talking to them, or of the situation, or of the diagnosis? What is their agenda?
I nvitation	Ask permission to explain whatever you want to explain. This is the one everyone forgets: some people don't want to know whatever it is you think they need to know.
K nowledge	Explain whatever it is you have to explain. Do it gently, in a stepwise approach. Keep stopping to check that the patient is with you.
E motions	This is another one that everyone forgets: "You look shocked by what I've said." "Were you expecting something like this?" "How do you feel about what I've just said?" This is different from "Do you understand what I've just said?" Give emotions some space and some time.
S ummary and strategy	"To summarise, I think..."; "I suggest that the way forward from here is..."; "Is that OK?"

to assume a higher priority than technical judgments relating to the disease. Expert care in advanced disease, therefore, requires expertise in careful listening and responding to a patient's concerns and priorities.

The second skill taught and practised by the participants was that of new information or "breaking bad news". This skill is now routinely taught in medical schools (though often not in schools of nursing). However, many specialists have never been taught formally about the structures and sequence of skills thought to represent best practice. Like SAGE & THYME, the SPIKES model (box 2) seeks the patient's perception first, slows down the professional and avoids dangerous or insensitive assumptions. The model is presented below and was demonstrated (as SAGE & THYME was) using facilitated role play with an actor. Participants valued being reminded of this skill and being able to test the model within the context of advanced respiratory disease.

Interprofessional communication

Poor communication between professional groups is reported to be related to less efficient patient care [5]. FAULKNER [6] described the high emotional cost to the health professional of working in palliative care and attributed a large proportion of that cost to communication difficulties within the professional team. In advanced illness, the complexity of patients' problems increases the number of people involved and so heightens the importance of collaborative working [7]. There is clearly a danger of compartmentalised working as opposed to effective teamwork.

In planning the course, we developed a communication model that aimed to empower participants to raise issues with professional colleagues where there was a lack of collaborative working. This can often occur in hierarchical

teams when junior members find it difficult to raise concerns about patient care with more senior team members. Conflict situations were acted out in the classroom to explore the dynamics, and strategies for conflict resolution were explored. We experimented with a model we called "You – the patient – me" (box 3) as a guide for health professionals to address colleagues within hierarchical professional teams.

Course participants discussed the value of these models in the classroom and were encouraged to apply the learning in their clinical practice between course study days. They applied each of the three models to respiratory cases through interactive demonstrations using actors. This served to translate the theoretical models relating to consultation skills to the reality of caring for people with advanced respiratory disease.

With respect to SAGE & THYME, there was general agreement that the model provided a structure to assist healthcare practitioners to explore patient concerns and know what to do with them and then a way to move out of the discussion. As a comment from a course participant suggests, the model "provided a

Box 3 You - the patient - me**You**

"I know you are busy."
"I know you know this patient very well."

The patient...

"...has a lot of different problems and concerns."
"...needs input from a range of people."
"...will be well served if we can work together as a team."

Me

"I have some concerns about..."
"I have assessed..."
"I have a contribution to the team and would be grateful for a chance to be heard."
"I have extra information about..."

structure and framework with which to utilise our skills" for dealing with a distressed patient. SAGE & THYME "reminded us to ask during consultations about feelings, but then tells us how to react to those feelings of grief or anger".

Symptom management

The symptom burden in advanced respiratory disease requires health professionals to practice with confidence and within the available evidence.

Breathlessness

Several studies have demonstrated that patients with advanced respiratory disease experience a high incidence of breathlessness towards end of life not dissimilar to those patients with lung cancer [8–10]. TWYGCROSS and WILCOCK [11] describe breathlessness as being the most common symptom in the last days of life, and EDMONDS *et al.* [12] describe it as being the greatest predictor of an increased chance of a hospital death and as causing the greatest distress to carers. However, course participants reported uncertainty about the use of opiates and benzodiazepines in advanced respiratory disease and how to manage breathlessness. It is clear that a good assessment of breathlessness needs to be made in order to clarify whether there are any precipitating factors such as infection, anaemia, pulmonary embolism, pneumothorax or hypoxia and to treat any specific cause. General symptomatic measures can be adopted for mild breathlessness, including a calm, reassuring manner, adopting a more comfortable position and providing a fan or opening a window. Other nonpharmacological interventions can be incorporated into the general management. These include the following.

- Breathing education
- Relaxation and visualisation
- Distraction therapy
- Massage
- Activity management and energy conservation techniques
- Noninvasive ventilation as a palliative tool

In order to clarify the situation around the use of opioids and benzodiazepines we sought to dispel the myths and present the evidence. Table 1 is a distillation of the discussions.

Opioids affect the perception of breathlessness by interfering with the response in the cerebellar vermis and medial pons. By modulating the perception in the right posterior cingulate gyrus, which is the area of the brain that plays a part in emotions and cognitive behaviour, the hypothesis is that opioids ease the perception of breathlessness in the same way that pain is relieved. Given in small doses, they will not alter the respiratory drive – a concern of many of our delegates. At larger doses, opioids would affect ventilatory drive and reduce consciousness.

A systematic review of nine studies (eight in chronic obstructive pulmonary disease (COPD) and one in lung cancer) with a total of 116 patients found that there was a small but statistically significant improvement in breathlessness (with no effect on exercise tolerance or adverse effect on arterial blood gases) with small oral doses of opioids [13]. BRUERA *et al.* [14] suggested that with opioid-naïve patients, 2.5 mg immediate-release morphine every 4 hours may be sufficient to relieve breathlessness by 50%. In patients on controlled-release morphine, only 25–100% of the breakthrough dose for pain relief would be necessary to relieve symptoms of breathlessness. Benzodiazepines were useful for moderating anxiety and panic and may have an anxiolytic and sedative action. Sublingual lorazepam (0.5–2 mg) for acute breathlessness or 5 mg diazepam orally at night have been

Table 1 *Myths and evidence in advanced respiratory disease for the symptom of breathlessness*

Myths	Evidence
Morphine is dangerous in advanced respiratory disease and may cause respiratory depression	116 patients studied showed small but statistically significant improvement in symptoms. There were no adverse effects on arterial blood gases. This systematic review showed that opiates are helpful for treating breathlessness [13] Morphine at 50% of analgesic dose relieved dyspnoea by 50% [14]
Benzodiazepines are dangerous in advanced respiratory disease and could cause hypercapnia	Benzodiazepines can be effective but should be used with caution [15]

found to be useful, but their use needs to be monitored [15].

Depression

Fear, sadness, perplexity and anger are normal responses to the news that someone has an incurable illness. With mobilisation of internal coping resources, family support and some professional care, this usually resolves within a few weeks for the majority of normal individuals. It is common to have some relapses with an increase in symptoms or after an acute exacerbation; however, depression should not be regarded as a natural and understandable state in chronically ill patients. Ongoing depression needs assessment and treatment. There are some associated risk factors that might be useful to the clinician in diagnosing depression. These include the following.

- Personality traits, both rigidity and pessimism
- Other existing life events
- Lack of support
- Inability to express emotions
- History of psychiatric illness
- Previous mood disorder
- Alcohol and/or drug abuse

Health professionals should look for certain clinical features in an individual they suspect is depressed. These include the acknowledgement of a depressed mood most of the day for most days for >2 weeks as well as reduced pleasure and interest in usual activities, including the following.

- Change or loss of appetite
- Insomnia or restless sleep
- Fatigue
- Loss of concentration and lack of interest
- Loss of confidence
- Loss of hope
- Guilt

Depression can be graded into mild, moderate or severe according to the number of symptoms present and for how long. The UK National Institute for Health and Clinical Excellence (NICE) has provided a stepped care model for recognition, assessment, nonpharmaceutical management and pharmaceutical treatment of depression (figure 1) [16].

It is important that clinicians do not presume that depression is a natural disorder associated with advancing disease. It needs treatment and management in its own right. It should also be noted that depression is associated with an increased frequency of exacerbations of COPD.

Anxiety

Like depression, anxiety is an abnormal response that can manifest itself in a variety of ways ranging from sweating to panic attacks and phobias. Other symptoms of anxiety include the following.

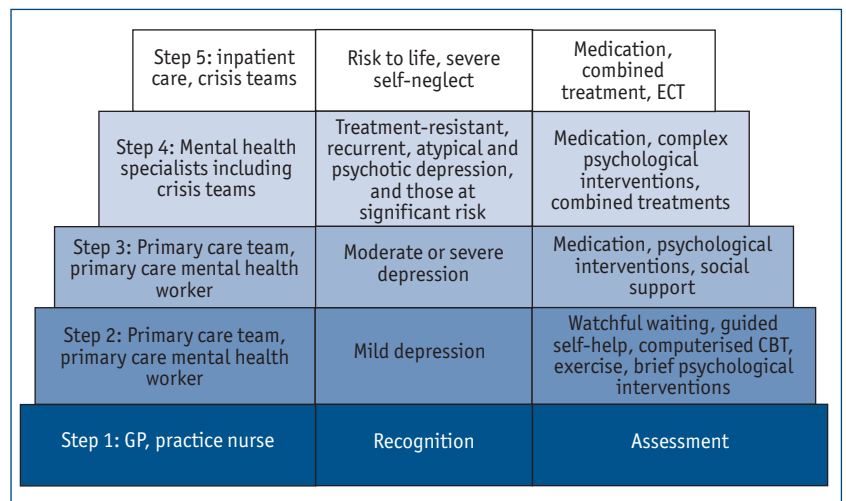
- Irritability
- Insomnia
- Nightmares
- Indecision
- Diarrhoea
- Tachycardia
- Tachypnea
- Nausea
- Pallor
- Tremor

Some people may be in a permanent state of acute worry that may vary in intensity. This can be due to changes in their illness or it may be due to other problems that have become heightened due to the illness, such as financial worries or relationship problems. Individuals may have a fear of death or hospitals, or some deep-seated unresolved fear that has become heightened with advancing illness. Exploring and understanding the anxiety can help, with a supportive relationship from family, friends and professionals. Other treatments may include:

- Anxiety training and management
- Psychotherapy
- Cognitive behavioural therapy
- Complementary therapy and relaxation
- Hypnotherapy
- Benzodiazepines
 - Lorazepam 0.5–1.0 mg sublingual as needed
 - Diazepam 2–5 mg nocte or up to three times per day
 - Temazepam 10–40 mg nocte
- Antidepressants

Figure 1

The NICE (2007 amended) Stepped Care Model. ECT: electroconvulsive therapy; CBT: cognitive behavioural therapy; GP: general practitioner. Each step represents increased complexity of intervention, with higher steps assuming interventions in previous steps.



Planning ahead to improve end-of-life care

Structured frameworks of care, which focus on planning ahead, have received much attention in the past decade. Patients with advanced respiratory disease can benefit from such anticipatory coordination if the professionals they meet are informed and motivated to learn from cancer care. While some respiratory conditions, such as idiopathic pulmonary fibrosis (IPF) and lung cancer, can be aggressive and short in duration, others, such as COPD, may involve a slow and uncertain disease trajectory over a number of years. The avoidance of distress often involves anticipating predictable problems and planning ahead. Underlying the three frameworks currently being used is the fact that suffering and death are ultimately unavoidable. The role of health and social care professionals is to ensure that predictable and unnecessary suffering is avoided. The courage to embark on uncomfortable conversations with patients and families can be developed through training as described above. In order for teams to avoid predictable and unnecessary suffering towards the end of life, organisation and planning are essential. The three frameworks are summarised below.

1. Advanced care planning

Advanced care planning involves asking the patient, while he or she is still relatively well, to consider what they would want when or if they become more ill. Such discussions require great sensitivity and, sadly, are rare. Some patients do not wish to discuss dying while they are focused upon living. However, a great deal of developmental work in the UK through the Preferred Priorities for Care (PPC) project appears to have raised the confidence of health professionals to ask these questions [17, 18]. Furthermore, once patients and families have become involved in such planning, there is some evidence of reduced use of hospital and a greater sense of control for patients and families in the late and final stages of illness.

2. The Gold Standards Framework

The Gold Standards Framework (GSF) is a different but complementary tool to PPC. GSF is, in essence, a structure around which care for people with advanced disease is organised [19]. Developed within community care, it is now in

use in one-third of UK community care teams. Patients who are thought by the health professionals to be in the last year of life are placed on a supportive care register, and become high-priority patients within the case-load of the community practice. Special treatment includes being allocated a key worker (commonly a community nurse) and seeing the same doctor at each appointment.

3. The Liverpool Care Pathway

The Liverpool Care Pathway (LCP) is complementary to the PPC and the GSF but is designed to organise the last days and hours of life [20, 21]. GSF has been developed in the community and care homes, while LCP has had its greatest impact in hospitals. However, the tools are becoming established in all healthcare settings. LCP challenges the health team to notice when death is likely within days or hours. In respiratory medicine, this requires health professionals to develop their clinical judgement as to when a "tipping point" has been reached. Case review, multi-professional discussion and learning from colleagues in other disciplines may improve this judgement. Communications skills training will foster, in health professionals, the courage and sensitivity to share dilemmas with patients and families relating to the point at which further investigation and treatment ceases to be beneficial. For some patients, this will come as a relief, for others it will cause sadness or come as a shock. There are clear advantages, however, to making the decision: nonbeneficial and intrusive tests and treatments can stop; clear communication with patient and family can take place; symptoms can be managed as per protocols; and the team can focus upon the avoidance of unnecessary suffering for both patient and family. Where used, the LCP has been shown to guide care in a way which controls pain, agitation, nausea and vomiting, and breathlessness [21]. Good evidence-based protocols will not remove all suffering from the process of dying. Some people will continue to die quickly and peacefully, while others will continue to have slow, drawn-out deaths. By adopting the LCP, health professionals can reassure themselves that an individual dying in their care will have high-quality symptom control.

Prognostication

It is generally thought to be easier to know when a patient with cancer is approaching the final months, weeks and days of life than it is with long-term conditions such as heart failure, Alzheimer's disease or COPD. Within respiratory

medicine, lung cancer and IPF may seem more predictable than Duchenne muscular dystrophy or motor neurone disease. Where the prognosis is uncertain, it is perhaps incumbent upon health professionals to develop a heightened awareness of the clinical and personal signs of deterioration. Research will have a role, but clinicians of all professions in respiratory care need to discuss and reflect upon their experience to ensure that the clear advances in end-of-life care are not denied to their patients. It is perhaps lazy to act as if chronic conditions were infinitely treatable. Each condition and each patient requires a unique combination of life-prolonging treatments coupled with approaches and interventions designed to anticipate and avoid unnecessary suffering. Prognostic indicators have been suggested, including pulmonary function testing and mobility [22] but in broad terms health professionals could simply ask themselves the following questions:

"Would I (we) be surprised if this patient died in the next 12 months?"

Alternatively

"Would I be surprised if this patient were still alive in the next 12 months?"

If the judgement of the team is that the patient is likely to die in the next year, this should be a trigger for action. Are the patient and family aware of the gravity of the situation? Does the team have the necessary skills to discuss it with them? Does the team know about advance planning? Should this patient now be considered for the GSF to coordinate and prioritise the support they will need?

"Would I (we) be surprised if this patient died in the next few days?"

Alternatively

"Would I be surprised if this patient were still alive in the next few days?"

If the judgement of the team is that the patient is likely to die in the next few days or hours, this again should be a trigger for action. Are the patient and family aware of the gravity of the sit-

uation? Does the team have the skills to discuss it with them? Is there a reversible precipitant? Is it in this patient's best interests to further investigate and further treat the precipitant? Does the team feel that a tipping point has been reached? Should this patient now be considered for the LCP, in order to coordinate the care and optimally manage the suffering commonly seen as people die? Does the team have the skills to discuss the likelihood of death with the patient and family?

Conclusion

During the 3-day course, advanced care planning, the GSF, the LCP for the dying patient and symptom-control issues were explored. Participants were encouraged to discuss and apply these models of care to their patient populations and typical case scenarios were chosen for discussion. Emphasis was placed upon communication skills. Having practised some of the models of communication used to hear and address concerns, break bad news or deal with conflict within the team, participants felt that they had tools useful in practice. Finally, understanding the models of coordination of palliative care in cancer and applying these to patients with advancing chronic disease was thought to be helpful.

Managing end of life in advanced respiratory disease will remain within the expertise of the speciality. Few people will understand respiratory medicine and its disease trajectories better than the specialists who diagnose and treat such patients. They are best placed, for example, to separate out acute reversible episodes and background chronic deterioration in individual patients. Developing the confidence and skills to care expertly for the dying is as important as maximising treatments and curative therapies. Patients will continue to die from respiratory disease. Managing end-of-life care successfully can be a rewarding experience for a specialist who has been a trusted clinician throughout the disease journey and a comfort for both patient and carer.

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Useful links

Department for Constitutional Affairs. *Mental Capacity Act 2005* www.dca.gov.uk/menincap/legis.htm#reldocs

The Liverpool Care Pathway for the Dying Patient www.mcpcil.org.uk/liverpool_care_pathway (see review on page 155 of this issue of *Breathe*).

National Health Service End of Life Care www.endoflifecareforadults.nhs.uk/eolc/framepath.htm

The National Gold Standards Framework Centre England www.goldstandardsframework.nhs.uk/

For more information and booking details for next year's course, please see www.ams.co.uk/events/BTS%20short%20course%20booklet.pdf

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Further reading

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