

Integrated care of the patient dying of nonmalignant respiratory disease

Educational aims

- ▶ To understand the current limitations to providing the best care to patients dying of nonmalignant respiratory disease.
- ▶ To understand how careful communication and support from the multidisciplinary team can improve this.
- ▶ To discuss the role of an integrated care pathway for use with dying patients.
- ▶ To understand the limitations of current knowledge and the importance of further research in this area.

Summary

The development of palliative care as a speciality in its own right has led to great improvements in the care of dying patients, but both funding and service arrangements have meant that the majority of these improvements have been seen in patients dying with malignant diseases. Here we will consider how, by making the best use of current resources, we can improve the care and support given to patients dying of nonmalignant respiratory disease, as well as providing support to their families and carers.

Chronic respiratory disease accounts for one-third of all deaths in Europe. Chronic obstructive pulmonary disease (COPD) is the leading cause of nonmalignant respiratory disease and, by 2020, will be the third leading cause of death worldwide [1]. In the period leading up to death, only 2–3% of those dying from any nonmalignant disease access specialist palliative care. Across Europe and the developed world, most people with chronic respiratory disease die in hospital, although it is known that few would make this choice. Indeed, only 12% of all UK deaths are in hospices, and very few of these patients have nonmalignant diagnoses. Currently, the vast majority of palliative and end-of-life care provided to those with nonmalignant disease is supplied by family, carers and nonspecialist community healthcare professionals. Therefore, it is perhaps not surprising that patients without a

cancer diagnosis are reported to receive inadequate end-of-life care [2].

For the majority of patients with chronic respiratory disease, maximal medical therapy helps to reduce breathlessness and cough and to improve exercise tolerance, but patients continue to have significant symptoms that impact on their health-related quality of life. In these patients, the traditional model of curative care with a switch to palliative care when reaching the terminal phase of life is not satisfactory; rather, we must change our practice to allow both curative care and palliative care to run side by side (figure 1). This article will focus on the care of patients dying of nonmalignant respiratory disease, with some discussion of palliative care approaches in the last weeks or months of life, but concentrating on care in the last weeks or days. The article will not discuss medical management of such patients in detail

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Provenance

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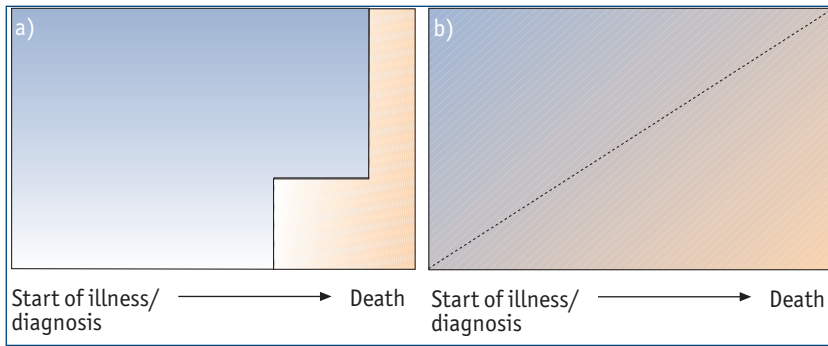


Figure 1
The traditional medical model of care (a) suggests that treatment aimed at cure of the disease should continue until end of life is near, and only then should we consider palliative care. This model is often unsatisfactory for those dying with nonmalignant respiratory disease when severe symptoms may be present for many months prior to death. In these patients, curative and palliative care approaches can be used hand in hand to optimise the patient's functioning and quality of life (b).

but, rather, will address the holistic care of patients, with emphasis on communication, care planning and involvement of the multidisciplinary team.

What are the current limitations to providing excellent end-of-life care?

The course of disease and, therefore, the prognosis in patients with lung cancer is often predictable, while this is often not the case in patients with nonmalignant respiratory disease. The Study to Understand Prognosis and Preferences for Outcomes and Treatment (SUPPORT) aimed to improve decision making and reduce the frequency of a mechanically supported, painful and prolonged process of dying [3]. In total, >4,000 patients with one or more of nine life-threatening diagnoses, including COPD, were entered into the study. Although this was an American study, where admission to the intensive care unit (ICU) and subsequent intubation is, perhaps, more common than in many parts of Europe, the authors found that patients with COPD were much more likely to die in the ICU on mechanical ventilation and with significant breathlessness. They also looked at the utility of prognostic models of survival, using the Acute Physiology and Chronic Health Evaluation II score and showed that, even as close as 5 days before death, patients with lung cancer were predicted to have a <10% chance of surviving for 6 months, while those with COPD were predicted to have a >50% chance.

Healthcare professionals have difficulty in discussing prognosis in the face of such prognostic uncertainty [4] and, in addition, many feel inadequately prepared to have such discussions. In practice this means that communication regarding end of life is often avoided or delayed in

patients with chronic respiratory diseases [5]. Such discussions often take place for the first time very late in the course of the disease and, not infrequently, when the patient is in respiratory failure and decisions need to be made whether to ventilate or palliate. Indeed, studies have shown that a minority of patients with moderate-to-severe COPD have discussed end-of-life issues and treatment preferences with their physicians, although the majority would value this opportunity [6]. Even when patients themselves do not wish to know their prognosis, it is important to understand the needs of families and carers, as prognostic information may help them to prepare, not only in caring for their loved one, but also for their death.

J.R. Curtis (University of Washington, Seattle, WA, USA) has perhaps done the most work in this area of communication. He has identified several important topics that COPD patients would value the opportunity to discuss with their physicians and other healthcare professionals, and which, at present, are often not discussed in any detail (table 1). Although not yet common in most parts of Europe, in the USA the use of advance directives has increased substantially over the last decade and is now nearly universal among residents receiving palliative care and/or hospice services. There is limited evidence to suggest that patients who have advance directives have lower levels of anxiety and depression, and possibly higher levels of satisfaction with their involvement in end-of-life care, than those who do not have advance directives [8].

A great inequality currently exists in access to services between patients dying with malignant and nonmalignant respiratory disease. This is in part due to lack of resources, which constrains the wider availability of palliative care programmes in the healthcare system. GORE *et al.* [9] examined 50 patients with severe COPD (forced expiratory volume in one second <0.75 L) and at least one admission with hypercapnic respiratory failure,

Table 1 Components of end-of-life care that patients would like to discuss with their physician [7]

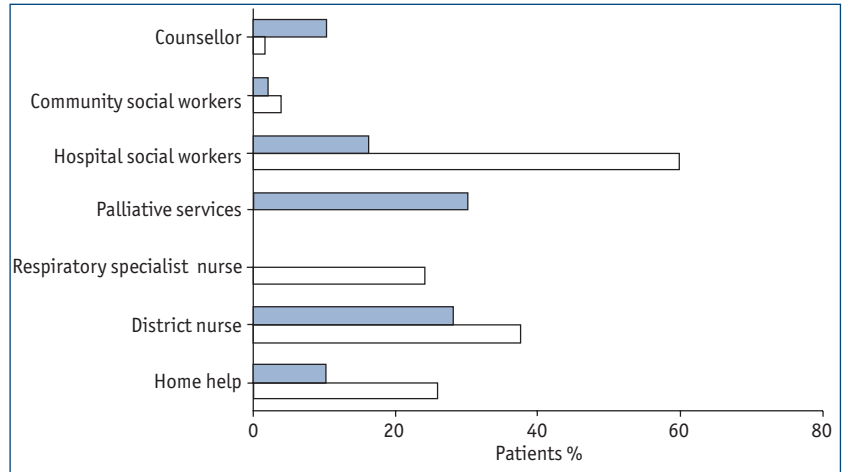
- Their diagnosis and disease process
- The role of the treatments in improving symptoms, quality of life and duration of life
- Their prognosis for survival and for quality of life
- Advance care planning for future medical care and exacerbations
- What dying might be like

and 50 patients with unresectable nonsmall cell lung cancer (NSCLC). Using standardised quality-of-life tools, semi-structured interviews and review of documentation, they found that COPD patients had significantly worse activities of daily living and physical, social and emotional functioning than the patients with NSCLC. They also noted high levels of anxiety and/or depression amongst COPD patients that were often undiagnosed. COPD patients were generally better provided for in terms of aids and appliances, but very few had received counselling and none had received help from specialist palliative care services (figure 2). A recent Canadian study suggests that this situation is unlikely to have changed, with only 2.8% of COPD patients receiving palliative care at home in the period prior to death [10].

Often, the most difficult step in managing patients dying with nonmalignant respiratory disease is in diagnosing dying. There are many barriers to recognising and diagnosing dying:

- Hope that the patient might recover.
- Disagreement among members of the multidisciplinary team that a patient is nearing the end of life.
- Failure to recognise key symptoms and signs.
- Reluctance to communicate with the patient and/or relatives that the end of life is approaching.
- Fear of foreshortening life.
- Medico-legal issues including concerns about withdrawing and withholding treatment.

In 2004 and 2005, all inpatient referrals of patients with nonmalignant respiratory disease to the specialist palliative care team (SPCT) over a 12-month period in a large teaching hospital in Liverpool, UK, were audited. Of 1,181 referrals to the team, 937 were cancer patients and 144 were not cancer patients. Only 38 (3%) of those identified had nonmalignant respiratory disease. Almost half of the patients referred had COPD (figure 3). Although the SPCT responded to requests for help and support very rapidly, with almost all patients being reviewed within 24 h of referral, five patients died prior to review (within 2 h of referral) and in two cases, the medical team no longer wished for involvement from the SPCT when they arrived on the ward. Most patients were referred for help with symptom control, usually breathlessness, but expert advice with psychological support, discharge planning and terminal care was also sought. Figure 4 shows the support provided by the SPCT to staff, patients and carers. Of the 31 patients reviewed,



19 died within a week of referral, the vast majority within 48 h of referral, and all in hospital. Only one patient was discharged to a hospice. The conclusions from this small study are that very few patients with nonmalignant respiratory disease are referred to specialist palliative care services and of those that are referred, this frequently occurs too late in the disease trajectory for the SPCT to be of any help.

Figure 2 Services provided to patients with severe COPD □ versus nonsmall cell lung cancer ■. Reproduced from [9] with permission from the publisher.

How can we improve end-of-life care?

The use of an integrated care pathway can aid healthcare professionals in providing better end-of-life care to patients, independent of their diagnosis. The Liverpool Care Pathway for the dying patient (LCP) is one example of such a pathway. It was developed by the SPCT at the Royal Liverpool and Broadgreen University Hospitals National Health Service (NHS) Trust and the Marie Curie Hospice, Liverpool, UK. It was recognised as a model of best practice in the NHS

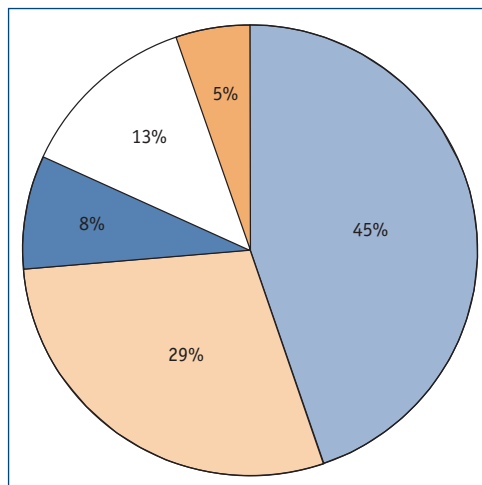


Figure 2 Diagnosis of patients with non-malignant respiratory disease referred to SPCTs for end-of-life care. ■: COPD (n=12); ■: pulmonary fibrosis (n=11); □: pneumonia (n=5); ■: other respiratory failure (n=2); ■: other (n=3).

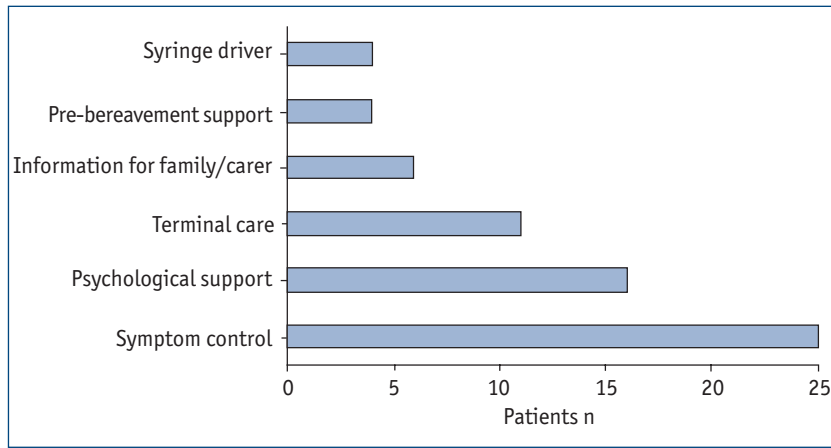


Figure 4
The support provided by the SPCT for dying patients. Some of the 31 patients received more than one intervention.

Beacon Programme and was subsequently incorporated into the cancer services collaborative project and the UK's national end-of-life care programme [11]. In 2006, it was recommended in the Our Health, Our Care, Our Say white paper [12] as a tool that should be rolled out across the UK and by the end of June 2007, there were 1,128 registrations from organisations within England (19% from hospitals, 9% from hospices, 43% from the community and 29% from care homes). It is also used in many centres across Europe and, indeed, worldwide.

The pathway can be used in any healthcare setting, including the patient's home, and provides healthcare professionals with a framework within which to assist in caring for dying patients, regardless of diagnosis. The key themes of the pathway are as follows.

- Improve the knowledge related to the process of dying.
- Improve the quality of care in the last hours and days of life.

The LCP replaces all other documentation and has, wherever possible, been developed using evidence-based guidelines. It may be utilised in any patient when the multidisciplinary team has agreed that the patient is dying, and two of the following may apply: the patient is bed-bound; is only able to take sips of fluid; is semi-comatose; or is no longer able to take tablets. The pathway begins with an initial assessment of the patient, which must include evaluation of physical condition, comfort measures, psychological insight, religious and spiritual support, and communication both with the family and primary/secondary healthcare team. Subsequently, each section has a number of goals which suggest the standard to be strived for and should a goal not be achieved, a 'variance' is recorded. The pathway provides guidance on key aspects of care (see box).

What results can you expect using an integrated care pathway?

We started to use the LCP in patients with lung cancer, and only once the multidisciplinary team had gained in confidence using the tool in patients with malignant disease did we move on to use it in the majority of patients dying on our wards. From February 2007 to the end of January 2008, in our 90-bed chest unit, we used the LCP on 110 occasions: 69 (63%) out of 110 patients had lung cancer, 43 (39%) out of 110 had nonmalignant diagnoses and in the remaining 26 patients the diagnosis was not recorded on the LCP. Two of the 110 patients (one with lung cancer and one with COPD) did not die and were taken off the pathway. We have compared the outcomes in 30 patients with nonmalignant disease and 30 with lung cancer, in terms of achieving the goals set by the LCP, and found that there was no difference in the length of time prior to death that patients were commenced on the LCP (mean 40 h for those with nonmalignant respiratory disease versus 46 h for those with lung cancer). Figure 6 depicts the outcomes in these patients in terms of achieving the various goals. There were no differences in the assessment and discontinuation of inappropriate medication, the prescription of as-required subcutaneous medication, or the cessation of inappropriate nursing and medical interventions between the groups. Medication *via* a syringe driver was prescribed in a smaller proportion of patients with nonmalignant respiratory disease than those with lung cancer. A greater proportion of patients with nonmalignant respiratory disease were comatose at the time of commencing the LCP (figure 6), so frequently the patient's insight into their condition could not be assessed or further discussed with them. This perhaps reflects the difficulty in diagnosing dying in this patient group, with clinicians waiting for very clear signs that the patient is dying before commencing end-of-life care.

What remains to be done?

It is imperative that we continue to offer the best medical care in order to improve quality of life

Key aspects of the LCP

Symptom control

Guidelines for the treatment of pain, agitation, nausea and vomiting and respiratory tract secretions can be found at the end of the pathway. Each symptom section contains advice about appropriate prescribing and drug doses, as well as recommendations on how to respond to a patient's emerging symptoms and response to therapy (as an example, the algorithm for the management of pain is shown in figure 5). Ongoing care includes, every 4 h, a review of pain, agitation, respiratory tract secretions, nausea and vomiting, dyspnoea, and other symptoms. There should also be a review every 4 h of mouth care and application of medication and, every 12 h, a review of mobility/pressure areas, bowel care, psychological insight, religious support and care of the family.

Anticipatory prescribing of medication

As-required subcutaneous medication for symptomatic control.

Discontinuation of inappropriate interventions and comfort measures

Inappropriate medical interventions may include blood tests, oral or *i.v.* antibiotics, other *i.v.* drugs and fluids. It should be recorded that the patient should no longer be resuscitated in the event of a cardiorespiratory arrest and that this knowledge has been shared amongst all members of the multidisciplinary team. Implanted cardiac defibrillators should be deactivated. Routine nursing interventions, such as a regular turning regime, should be stopped and, rather, the patient should be repositioned for comfort only. It may be appropriate to consider a pressure-relieving mattress and appropriate assessments should be carried out regarding skin integrity. Measurement and recording of vital signs should be stopped and monitors, such as pulse oximeters, removed.

Communication with other healthcare professionals

Such communication will obviously be dependent on the healthcare setting in which one is working but, for example, if the patient is dying in a hospital or hospice, it is vital to inform the patient's primary care physician both that he or she is dying and of the death once this occurs.

Psychological and spiritual care

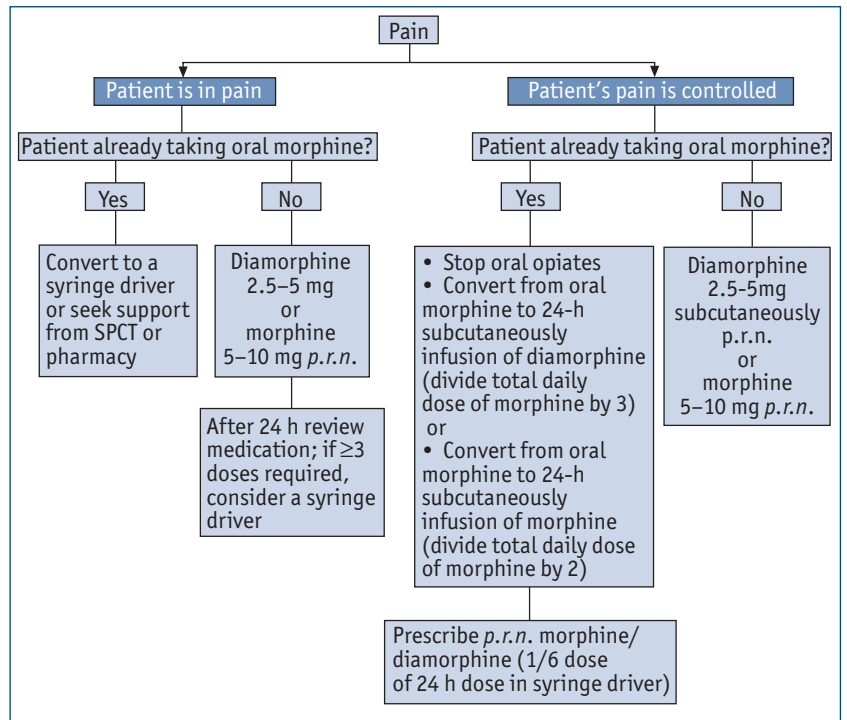
The patient's ability to communicate must be assessed. This should include appraisal of any problems with language which might require help from an interpreter as well as issues such as dysphasia and deafness. The family and patient (where appropriate) must be made aware that the emphasis of care has moved from 'cure' to palliation. The religious tradition, if any, of both patient and family should be identified and pastoral support offered. In view of the patient's religion, any special needs, both around the time of dying and after death, should be identified.

Care of the family (both before and after the death of the patient)

In our experience, these are areas that are often neglected. Information should be provided on practical aspects of hospital visiting, such as car parking, accommodation and the availability of food and drink for the carers. Additional information regarding how to proceed once the relative has died must also be shared with the family, with information about how to collect a death certificate and the deceased's valuables and belongings. Written information in the form of a bereavement booklet is often appreciated.

Figure 5
Guidelines for the management of pain.

and, where appropriate, prolong life in our patients with chronic respiratory disease. Evidence suggests that health-related quality of life, even when measured by the best tools we have available, such as the St George's Respiratory Questionnaire, does not help us to predict end-of life treatment preferences for individual patients with moderate to severe COPD [13] and we must take extreme care not to impose our own values of what is a worthwhile quality of life on these patients when taking into account their end-of-life care planning. The use of noninvasive ventilation (NIV) has revolutionised care for patients with moderate to severe COPD who develop type-2 respiratory failure during exacerbations, with many patients now surviving such episodes. However, across Europe, around one-third of patients who die in hospital from COPD receive NIV during their last hospital admission [14] and in some of these patients, the intervention is perhaps inappropriate. It is for these patients, as well as those with other



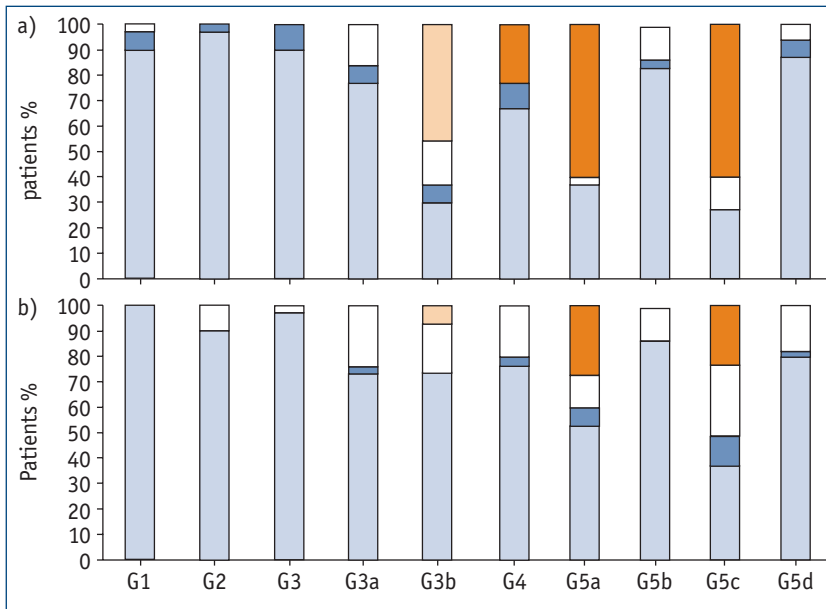


Figure 6
 The LCP: achievement of initial assessment goals in patients with a) nonmalignant respiratory disease versus b) lung cancer. ■: achieved; ■: variance; □: missing; ■: comatose; ■: N/A. G1: medication assessed and discontinued; G2: as-required subcutaneous medication prescribed; G3: inappropriate medical interventions discontinued and clear documentation of 'Do not resuscitate' order; G3a: discontinuation of inappropriate nursing interventions; G3b: syringe driver set up within 4 hours of doctor's request (medication via syringe driver was prescribed in a smaller percentage of patients with nonmalignant disease than with cancer); G4: ability of the patient to communicate assessed and addressed; G5a: patient's insight into the condition; G5b: family's insight into the condition; G5c: patient's recognition of dying; G5d: family's recognition of dying. There were more comatose patients among those with nonmalignant disease than those with cancer (60 versus 25%).

For more information about the Liverpool Care Pathway, please visit www.mcpcil.org.uk/liverpool_care_pathway

terminal nonmalignant respiratory diagnoses, that we must strive to further improve care.

Communication with patients about their diagnosis and prognosis, even during the final stages of the disease in those with nonmalignant respiratory diagnoses, is lacking as is support from specialist nurses and SPCTs. A recent British Thoracic Society/National Council for Palliative Care survey of respiratory physicians in England, Wales and Northern Ireland revealed that 88% of respondents had no formal process for initiating end-of-life care discussions for those with nonmalignant terminal respiratory disease, and that while three quarters of chest physicians had support from specialist lung cancer nurses, 80% of those nurses did not extend care to those with nonmalignant disease (M.R. Partridge, Imperial College London, London, UK; personal communication).

Conclusions

Although in recent years there have been

improvements in end-of-life care both for patients with lung cancer and those with nonmalignant respiratory diagnoses, there remains much work to be done. As healthcare professionals working in the field of respiratory medicine, we all have a responsibility to raise public awareness of chronic respiratory diseases, perhaps in particular COPD, which remains a diagnosis that is unknown to the majority of people and yet is among the leading causes of death in the world. Lord Darzi's recent UK report [15] states that everyone approaching the end of their life should be given support should they choose to die at home and we must improve access to end-of-life care for all to enable this. We must also continue to develop the training of physicians and other healthcare professionals in order to improve communication with our patients and their families, both earlier in the course of the disease and during the terminal phase. The use of integrated care pathways, such as the LCP described above, can aid communication and symptomatic relief, regardless of diagnosis, with involvement from the whole multidisciplinary team. Finally, this is a difficult area to research and there remains a lack of evidence to support best practice in many aspects of end-of-life care, from patients' and families' wishes regarding communication issues to the most effective methods of achieving good symptomatic relief. More research is urgently required into what patients near the end of life and their families need and want, and how we can best achieve this.

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