Nurses lack confidence in providing end of life care

Staff need more training, and time, to hold difficult conversations with patients. Jennifer Sprinks reports

MUCH HAS been done over the past decade to try to improve access to good end of life care for older people.

National strategies have sought to place a stronger focus on encouraging the general public and healthcare professionals to think about death and how to respond to it. Furthermore, they place a greater emphasis on giving patients the choice of how and where they would like to die, and the need for more education and training to improve staff competencies in providing end of life care. But there has been little focus on making staff more confident to help people plan that care.

RCN primary care adviser Lynn Young says: 'There seems to be a nervousness with nurses and doctors in terms of deciding when they need to have the conversation with a patient about how they want to receive their end of life care. They do not know when is the best time and what is the best way of approaching the subject.'

A report published by the National End of Life Care Programme (NEoLCP) states that nurses need to have wider access to training and support to improve their communication with people who are dying and their relatives. The report, Talking About End of Life Care: Right Conversations, Right People, Right Time, is the culmination of the NEoLCP’s study of training and education provision at 12 pilot sites across England.

With deaths likely to rise significantly in the next 20 years because of the ageing population, a wider range of nurses will be actively involved in providing end of life care, the report says. It calls for greater variety of training materials, such as e-learning, to be provided to staff in all settings and at all levels to create a cultural shift in the approach to end of life care planning (Box 1).

NEoLCP deputy director Anita Hayes says targeted communication training gives nurses skills and confidence to initiate difficult conversations about how a patient would like to receive their care at an early stage. 'It is an opportunity to start advance care planning and can improve the co-ordination of care across different agencies,' explains Ms Hayes. 'Delaying those conversations increases the likelihood of complaints, late referrals to palliative care services, unplanned admissions and inappropriate interventions in response to a sudden deterioration.'

Communication

The idea that good care is achieved by involving patients more in care planning has been given greater weight by the NHS white paper, Equity and Excellence: Liberating the NHS. Nevertheless, the NEoLCP report states patients’ needs are often not met because of poor staff communication and lack of involvement in decisions about their own care. It cites a survey conducted by the National Centre for Social Research which found that while 29 per cent of people had talked about their wishes around dying, only 4 per cent had written advance care plans.

Despite significant improvements since the national end of life care strategies were introduced in 2004 and 2008, experts say that people are still not getting their preferred place of treatment.

‘We have paid lip service to [the idea of] helping people die where they wish but we have not set up a system to allow that to happen,’ says Ms Young. ‘Many deaths are still taking place in hospital and we need to confront that.’

She explains that pre- and post-registration courses should place more emphasis on ‘high-level communication skills’ and teach nurses how to have difficult conversations at the start and during a patient’s care pathway, as well as show them how to offer reassurance and comfort once treatment has finished.

Independent nursing consultant Les Storey is the national lead for the Preferred Priorities for Care (PPC) programme, a process designed to help initiate and develop conversations between patients, carers and healthcare professionals about a patient’s preferred place of care and death.

He says staff need training on how to have these sensitive conversations earlier to ensure patients get their preferred place of care and death known right from the start.
Experts say nurses need to broach sensitive subjects, such as a patient’s preferred place of death, earlier on training is a problem. Organisations also need to ensure that staff have the time to have difficult conversations, he says.

Patients with dementia

Communication with patients who have dementia is one area where early conversations are essential. According to the Alzheimer’s Research Trust, one in three people over the age of 65 will die with some form of dementia.

Karen Harrison Denning, national practice development lead for Admiral Nurses at Dementia UK, says: ‘It is only over the past ten or 12 years people have considered that older people and dementia patients should have good access to end of life care.’ She explains that all nurses should receive some form of training in communicating end of life care issues during pre-registration training, with more specific training later on to suit the professional’s role.

Ms Harrison Denning says the earlier a nurse has the conversation with a patient about their end of life care, the better because many people with dementia can quickly lose the capacity to communicate. ‘People with dementia are a difficult group to provide end of life care to. There is a general assumption that a person with dementia can’t communicate, so why bother? There are many ways to understand a dementia patient’s communication or to develop other ways of making staff understood. Patients with dementia are often misunderstood, and frequently it is because of their behavioural changes, but much of it comes down to better communication.’

She says the system needs to ensure that carers and nurses are given the support and time to do their jobs well. ‘We are not valuing our older people and people with dementia because we are not valuing the staff,’ she says. ‘Over the past few years there has been significant improvement but I still do not feel the government has given the response that the demographics demand because of the number of people who will have dementia in the future.’

Another factor that can enhance an older person’s end of life care is spirituality. A recently published review on the future approach to providing spiritual care at the end of life, commissioned by the Department of Health, found a need to improve the education and training of the workforce in all aspects of spiritual care.

‘People are not having the conversations about what their preferences are in terms of what type of care they receive or where they wish to die. A lot of nurses are competent at end of life care but a lot of them are not confident; they are too worried about upsetting patients,’ he says.

Mr Storey says communication training should cover three basics:

■ Ask patients about their preferred place of care.
■ Ensure patients’ views are recorded.
■ Make information accessible so it can be shared with other staff.

Communication training on end of life care is available, but ensuring staff have support and time set aside by employers to do the training is a problem. Organisations also need to ensure that staff have the time to have difficult conversations, he says.

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