In the current situation where many patients with cancer have palliative chemotherapy, the line between active treatment and palliative care can become blurred. This can create particular challenges for community nurses around their communication with patients and families in terms of end-of-life care. Patients may have a myriad of disease- and treatment-related symptoms, and community nurses often require specialist knowledge to help individual patients manage these symptoms. In order to provide a comprehensive service it is vital that palliative care and cancer care teams offer effective support and education to community nurses so that they can provide compassionate but also informed care.

Anne Williams
Lymphoedema nurse consultant and researcher, Blantyre, Scotland

The fact that the Liverpool Care Pathway was misused is more a reflection of individual staff’s lack of skill than a criticism of the pathway itself. Just because a patient has reached the end of life is no reason for complacency. When studying for my master’s degree I remember reading Caring: The Compassion and Wisdom of Nursing by Gosia M Bryłczynska and being struck by the idea that caring is never so apparent as when it isn’t there. This set me thinking about how we define caring and how hard it is to measure. It also raises the question of who is ‘doing’ the caring — specialists or generalists? Increasing demand for services means that not all care can be ‘expert’, but it still needs to be guided and well informed.

Jackie Stephen-Haynes
Professor in tissue viability, Birmingham City University and consultant nurse, Worcestershire Health and Care NHS Trust

In each issue of the Journal of Community Nursing we investigate a hot topic currently affecting our readers. Here, Jason Beckford-Ball looks at an issue that refuses to go away — end-of-life care — and asks the question...

Do we need to start again with end-of-life care?

It goes without saying that death is difficult to talk about. Anyone who’s ever had to speak to a patient about death or discussed with a relative what might happen to their loved-one will know that each situation is different and that the topic of dying needs to be handled sensitively and with a healthy amount of compassion.

Unfortunately, however, rather than being lauded for their sensitive handling of end-of-life issues, nurses — and in particular, community nurses this time — seem yet again to be bearing the brunt of controversy.

Last year’s storm around the Liverpool Care Pathway (‘Death pathway damned’, Daily Mail) highlighted that it was not the pathway itself that was at fault when it came to easing people’s final days, but the fact that many staff, including nurses, treated it as a ‘tick-box’ exercise and came to rely on the pathway rather than their own clinical skills.

Dr Rachel Broadbent, writing in Geriatric Medicine, noted that, ‘Clinicians should remember that no pathway, plan, or protocol can be a replacement for good clinical judgement, compassion and care,’ (‘The death of the Liverpool Care Pathway’, Geriatric Medicine).

You’d imagine that a year on from the media storm that engulfed the Liverpool Care Pathway and all the official noise about changing end-of-life care for the better (‘Liverpool care pathway for dying patients to be abolished after review’, The...
"Community nurses under pressure over end-of-life chats' — ‘Community nurses may be being put under pressure to probe frail and elderly patients on their end of life wishes without the right support and training, say palliative care experts,’ writes Jo Stephenson in the Nursing Times, adding that, ‘the warning comes amid growing concern ... about the way these sensitive conversations are being handled’.

‘Death pathway damned: Mail campaign vindicated in devastating report on scandal of end-of-life treatment’ — referring to the Liverpool Care Pathway, Steve Doughty and Daniel Martin of the Daily Mail write that, ‘a devastating inquiry into the system used in hundreds of hospitals also shamed nurses and said their “tick box” treatment of the sick and vulnerable had been “uncaring, rushed and ignorant”‘.

Reading between the lines of Cummings’ double-speak, and taking into account all of the latest media coverage, the most telling charge seems to be that many community nurses see questions about palliative care as a mere formality and even something to be avoided. As Eileen Wardhere recently wrote in the JCN, ‘I felt that we ... were avoiding talking about death even though our patient was terminally ill. We were trying to “treat” death instead of delivering high-quality care,’ (How do we deal with the death of a patient, Journal of Community Nursing).

However, why is it nurses that are being singled out yet again? Its true that many community nurses do not undertake specific training to deal with patients at the end of life, but isn’t this what palliative care services are for? Should the average community nurse, as well as being an expert in wound care, skin care, continence, diabetes, respiratory care etc, also have to perfect skills in guiding people through death?

On the other hand, and without getting too philosophical about it, death is a part of life and perhaps nurses of any persuasion ought to have sufficient ‘people skills’ and compassion to discuss end-of-life care without hiding behind a form.

Perhaps, finally, the truth is more prosaic — that community nurses are human beings who are being asked to do their best with slim resources and, with the best will in the world, can’t get everything right, all of the time. So, do they need specialist training in end-of-life care...? JCN

Mutual trust is central and can take time to develop, particularly when multiple clinicians are involved. Listening to verbal and non-verbal cues is vital when sharing decisions about end-of-life care. Time is needed to avoid misunderstanding and ensure supportive care.

Sandra Olive
Respiratory nurse specialist, Norfolk, and member of the Association of Respiratory Nurse Specialists (ARNS), executive committee

The ancient adage ‘do unto others as you would have them do to you’ is a useful guide, particularly in end-of-life care where compassion must dictate our actions. But developing compassion takes time. With nurses’ resources stretched and ‘tick boxes’ taking over, are current expectations of the nursing role a poor fit for the provision of compassion? End-of-life care is complex and it is unfair to nurses to expect them to meet everyone’s needs.

Sally Lee
Social Worker, Dorset

Failures in communication are common when patients are unhappy about care.

Media watch

Guardian), we could have put this particular issue out of its misery?

It seems not. A recent Nursing Times article noted that, ‘Community nurses may be being put under pressure to probe elderly patients on their end-of-life wishes without the right support and training,’ (‘Community nurses under pressure over end-of-life chats’, Nursing Times). The article explained how growing numbers of patients and relatives are still complaining about how nurses handle sensitive conversations around death.

Nor was this simply a case of journalistic scaremongering — the article came on the back of the chief nursing officer (CNO) of England, Jane Cummings, commenting that, ‘There are thousands of great district and community nurses delivering compassionate care in a wide range of environments every day. They would never dream of asking patients where and how they would like to die in an insensitive or bureaucratic way,’ (Listening to important questions, www.england.nhs.uk).

OK, great — so there’s no problem, then? Except, Cummings went on to say, ‘Compassionate care should be at the heart of all conversations and relationships between a nurse and patient. Poor implementation of a document by individuals is no excuse for causing distress to our most vulnerable individuals is no excuse for causing distress to our most vulnerable patients and their families.’ Which sort of suggests that there may be a problem after all...

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