An overview of end-of-life care in the community setting

Angela Hall

End of life can be a frightening and uncertain time for patients and families and the role of the community nurse can be vital in easing this phase of life. This article outlines some of the issues that community nurses should be aware of when caring for a patient who is dying at home. It identifies the signs which signify that death is approaching, and explains the need for a change in care emphasis at this point. The author also outlines some key management aspects that can improve the quality of a patient’s death, including communication, care coordination, symptom and pain control, and support for nurses and carers.

KEYWORDS:
End-of-life care ■ Pain ■ Multidisciplinary working

People living in the community with chronic conditions, organ or system failure, cancers, or various forms of dementia are usually supported by healthcare professionals with interventions aimed at ensuring their wellbeing as they grow increasingly dependent (AgeUK, 2014).

Unfortunately, for all of these patients there comes a time when their condition has deteriorated beyond the point of recovery and when end of life is approaching. At this time, certain interventions, such as extensive wound care, become inappropriate.

The features that indicate that death is imminent within a few days include (National Cancer Institute, 2013):
- The patient becoming bed-bound
- The patient becoming semi-comatose
- Increasing weakness
- The patient being able to only take sips of fluid and having difficulty taking oral medication
- Skin changes — becoming paler, mottled or having a blue tinge
- The patient developing cold extremities
- The patient becoming withdrawn
- The patient experiencing a loss of bladder/bowel control
- The patient developing ‘rattling’ or ‘gurgling’ breathing sound.

When they get to this stage, many patients may wish to die at home surrounded by family and supported by community nurses, rather than in hospital (Hudson, 2010).

As a result of the Shipman inquiry, community nurses also need to ensure that there is a team consensus that the end of life is approaching — this is vital to protect patients from similar incidents. Nurses need to remember that their performance will be monitored and that record keeping and any care provided must be evidence-based (Home Secretary and the Secretary of State for Health, 2007).

CHANGING CARE EMPHASIS

Communication is fundamental to good end-of-life care (Charalambous, 2010), and is made easier where community nurses already know the patient and family and have been able to prepare them for death. The advent of palliative care registers and progress meetings in many areas helps community staff keep track of the status of the majority of patients before they reach the palliative stage, including those with non-cancerous conditions, such as end-stage dementia (Department of Health [DH], 2007).

Quality of death

For all those patients identified as dying in the community, the quality of their death should become the priority, and while nurses cannot hasten death, they should try to ensure a ‘good death’ wherever possible (Sandman, 2005). This involves keeping the patient and the family informed and providing the patient with as much dignity and comfort as possible through symptom and pain management. Community nurses are central to this idea of the good death (Adamson and Cruickshank, 2013).

It is important that patients die in as much comfort as possible, therefore, a holistic, person-centred and multidisciplinary team approach is needed — a range of clinicians add a diversity of knowledge and skills to the care team. That said, the structure of the multidisciplinary team should vary based on the patient’s requirements, with different
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professionals becoming involved at different times, e.g. Macmillan nurses, Marie Curie nurses, GPs, etc. The team should be guided by the patient’s wishes, aiming to ensure that they die with dignity. Impending death means that patients are often unable to perform certain activities of daily living, such as eating properly or going to the toilet — this loss of control can cause anxiety for the patient and the family. Community nurses can help with practical tasks, while also maintaining the patient’s privacy and dignity, e.g. when washing and dealing with urinary incontinence.

The situation in the community is sometimes complicated by distressed relatives and friends. However, research suggests that a good death reduces the risk of abnormal bereavement and post-traumatic stress for relatives (Jack and O’Brien, 2010). It is understood that patients who have discussed their plans for end of life experience less stress and are more prepared for the situation — knowing that their relative’s wishes have been met also helps family members to cope (Jack and O’Brien, 2010).

**Unnecessary treatment**

Importantly, patients and family members need to be informed about which treatments, medications or interventions may be beneficial and which are physiologically futile. Similarly, as end of life approaches, any non-essential medications are usually stopped. Community nurses should consider discussing with the family what will happen when the patient’s condition worsens and/or if an emergency arises, as well as issues such as ventilation and cardiopulmonary resuscitation (General Medical Council [GMC], 2010). In the author’s experience, family members can sometimes feel helpless and the change in emphasis of care towards the end of life brings a realisation that death is imminent. Family members may become angry and rather than seeking to prevent this, community nurses should help them express their emotions constructively.

Sometimes, patients nearing the end stage of their lives may be inappropriately transferred from home to hospital, or be started on treatments that they do not want such as parental nutrition (Partridge and Campbell, 2007). Community nurses should, where possible, act as an advocate to ensure patients receive appropriate care in their preferred location (this is often their own home). Similarly, community nurses have a key role in reducing unplanned hospital admissions and, as mentioned above, helping to ensure treatments are not started inappropriately (National Audit Office, 2008).

**The Liverpool Care Pathway**

The Liverpool Care Pathway was previously used in many areas (Marie Curie Palliative Care Institute, 2012). However, there has recently been a lot of controversy surrounding this end-of-life care pathway, with many questioning whether it has become the equivalent of euthanasia in practice, as many patients were placed on the pathway inappropriately and without adequate person-centred care.

Despite the criticism, however, many of its fundamental principles remain important and have been shifted towards ‘preferred priorities of care’ (an approach designed to help people think about, talk about and write down their priorities for care at the end of life) and advance care planning (NHS Improving Quality, 2011; While, 2012).

**Psychological support**

The psychological support that patients and families require from community staff is often considerable and good end-of-life care should be based on best evidence. The DH (2007; 2008) and the National End of Life Care Programme (2013) describe the aspects of best practice that should guide community nurses, including ensuring that, where possible, the patient is at the centre of decisions or that decisions are made with the patient’s best interests.
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at heart. Community nurses need to develop a therapeutic relationship with the patient and family in order to assess and manage the range of psychological problems that may arise, e.g. anxiety, panic, sadness or depression. While facilitating the expression of any fears or anxiety as well as providing information and support, community nurses should always seek to recognise their limitations and refer to other team members, such as psychologists or counsellors, where necessary.

Similarly, the DH Gold Standards Framework for palliative care (DH, 2007) describes the key aspects of care in terms of seven Cs:

- Communication
- Coordination
- Control of symptoms
- Continuity (including out-of-hours provision)
- Continued learning
- Carer support
- Care in the dying phase.

**COMMUNICATION SKILLS**

Community nurses should have the skills to facilitate open, honest and supportive communication during what is often a complex and emotionally difficult time. Using both verbal and non-verbal communication skills will help community nurses to assess what level of input is required by the patient and family, and the use of silence and listening skills are paramount, allowing time for reflection and re-enforcing the idea that staff have time to spend with the patient.

In the author’s experience, there is a danger that inexperienced staff may think they are required to talk and ‘do’ — however, simply being with the patient at the end of life is often more important for families.

Community nurses need to explore what aspects of end-of-life care may be troubling the patient and/or family. It is essential not to ‘block’ communication and to keep it open and honest by, for example, not changing the subject; not ignoring any emotional upset; not offering false reassurances; and not focusing exclusively on the physical aspects of care (Faulkner and Maguire, 1994).

In practice, community nurses should be able to:

- Demonstrate genuine warmth and empathy
- Use interpersonal skills to communicate effectively
- Explore the patient’s understanding of his or her illness and treatment by using open questions
- Help the patient and family to verbalise any concerns, thereby preparing them for what may happen, including potential psychological distress
- Explain the changing situation with sensitivity
- Provide honest communication without destroying hope (i.e. ‘Although we have stopped your treatment now, the team will manage your symptoms and support your family throughout.’)
- In some instances, just ‘being with’ the patient is often appreciated
- The nurse should always acknowledge the need to return later to continue talking if pressure of work means he or she cannot stay for longer at any particular visit
- Nurses should clarify their roles and the roles of others (family/carers) who may provide care and support
- The nurse should ensure he or she summarises and checks the patient’s and family’s understanding of any information, as well as documenting any discussions
- Where possible, nurses should always use specific end-of-life care documentation.

These interventions will help community nurses ensure that patients who choose to die at home are well-supported (Griffin and Sawkins, 2009).

**CARE COORDINATION**

Community nurses often coordinate care within the primary healthcare team and are the point of contact for other care providers. Depending on patient need, this may include liaising with palliative care nurses, Macmillan nurses, social services, private care agencies, the voluntary sector, and/or spiritual/religious leaders. Community nurses need to be able to facilitate a team approach, ensuring that patients and family do not get mixed messages from various multidisciplinary team members.

Community nurses often become a confidant for the patient who is dying at home, however, the Nursing and Midwifery Council’s (NMC, 2014) professional guidance regarding confidentiality still applies.

With regards to the coordination of care, community nurses should:

- Ensure that the psychosocial, spiritual and cultural needs of patients are central to care
- Monitor fundamental care such as personal and oral hygiene (if the family take on this role, they will need guidance on safe care)
- Coordinate any available resources, such as Macmillan nurses, etc
- Be aware of any services patients can access locally, for example, counselling or spiritual advice
- Coordinate any equipment (i.e. wheelchairs) to ensure that care is provided safely and according to local policy

**Five-minute test**

Answer the following questions about this topic, either to test the new knowledge you have gained or to form part of your ongoing practice development portfolio.

1 – What are the common signs that a patient is approaching death?
2 – Can you explain what Cheyne-Stokes breathing is?
3 – Do you understand why the Liverpool Care Pathway is no longer in use?
4 – Why are communication skills so important at end of life?
5 – Can you explain how pain management will play a crucial role in end-of-life care?
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**SYMPTOM CONTROL**

Symptom management, such as providing analgesia for pain, is often needed as the patient’s condition worsens, but requires robust ongoing assessment. Symptoms may require both pharmacological and non-pharmacological management. Community nurses need to anticipate any medication that may be required and ensure ready access to it (medication is often left in the patient’s home, for example). Some areas provide pre-prepared medication boxes to help prevent delays in administration.

There are some drugs that are commonly used drugs to help with symptom control (see below), particularly pain, and a dosage range is often prescribed, which can be adjusted as appropriate. Community nurses need a solid knowledge of the drugs commonly used in end-of-life care, which include:
- Analgesia (such as diamorphine)
- Anti-emetics (such as cyclazine or haloperidol)
- Drugs that help with agitation (such as midazolam)
- Respiratory drugs, such as hyoscine butylbromide, which is prescribed for respiratory secretions (these secretions can cause distress and restlessness in some patients, but community nurses should check if the bowel or bladder is distended to ensure retention is not the cause)
- Sedation may be needed, however, providing adequate analgesia and sedation are not the same as euthanasia (Sykes and Thorns, 2003).

**Pain assessment**

Pain is perhaps the symptom feared most by patients, and the perception of pain is affected by the emotional context in which it is endured (Scottish Intercollegiate Guidelines Network [SIGN], 2008). Pain perception will also be affected by fatigue, insomnia, anxiety, fear and cognitive impairment (Royal College of Physicians, British Geriatrics Society and British Pain Society [RCP/BGS/BPS, 2007]).

Assessment needs to establish the cause and type of pain as well as its physical effects, functional impact, and psychosocial factors. In the author’s opinion, the patient’s belief systems are also important as many people reconnect with spirituality/religion at the end of life, and unresolved issues can impact on the patient’s self-esteem and ability to cope with pain.

When patients are able, it may be helpful for them to take an active role in their pain management. If patients are unable to verbalise or indicate the location/intensity of their pain (i.e. semi-conscious patients), nurses need to watch them closely and use an observational pain assessment tool (SIGN, 2008), which will consider factors such as:
- Facial expressions
- Whether the pain is experienced at rest or on movement
- Are there skin changes at the pain site?
- Is the pain in an area supplied by a peripheral nerve?

The family may be able to guide the community nurse on the patient’s status between visits, but the nurse must bear in mind the decision-making paths that need to be put in place for patients who no longer have capacity (GMC, 2010). Ideally, family members will have discussed these wishes and the clinical team will be clear about how the patient wants to be cared for at the end of life. Healthcare professionals cannot ever take any actions to hasten death, but they can give analgesia to keep the person comfortable. When the patient is no longer able to consent and is dying, staff must act in his or her best interests (GMC, 2010).

The World Health Organization’s (WHO) analgesic ladder is helpful (WHO, 2014). If analgesia is not working there is little point changing to another drug of the same potency, and those with moderate or severe pain usually need opioid analgesia. However, not all pain types respond to opiates — bone pain for example, may benefit from non-steroidal anti-inflammatory drugs. The dose and titration need to be tailored to the individual and the severity of his or her pain, rather than relying on what is normally recommended for a patient with a similar diagnosis.

Generally, analgesia is best given regularly and any pain that ‘breaks through’ needs to be monitored. Breakthrough pain may be due to inadequate regular analgesia, but can also result from a different source of pain that is not responding to the prescribed analgesia (e.g. colic or neuropathic pain).

When administering pain relief for patients at the end of life, community nurses can make a significant contribution by:
- Keeping treatment simple
- Reviewing pain type, medication and dosage regularly
- Ensuring that medication doses are altered as pain severity changes, according to the relevant prescribing guidance
- Considering non-pharmacological approaches including the use of music and distraction, relaxation, massage, acupuncture, transcutaneous electrical stimulation, and touch.

**CONTINUITY OF CARE**

It is important that community nurses take steps to provide continuity of care, particularly when there are different agencies/professionals involved. For example, the care plan and any decision-making records should be easy to find (i.e. particularly if the patient is being treated at home). This is crucial in the case of resuscitation orders as on-call and ambulance staff may need access. Community nurses also need to make sure that in any 24-hour period family members and/or carers know who the point of contact in the care team is.

**Continued learning and support for community nurses**

Nurses who feel inadequately educated may experience more anxiety about looking after this patient group, which in turn means they will be less able to support dying patients. End-of-life care can be emotional, time-consuming and stressful for community nurses and it is important that they seek the help
and support of other interested parties, such as Macmillan nurses, hospices, GPs with an interest in palliative care, and specialist palliative care nurses. These associated healthcare professionals can be valuable resources in terms of symptom knowledge, pain management, and general guidance and support.

Commissioners and community teams need to identify their own requirements in terms of training, while nurses need to consider whether there is a forum to express any emotions resulting from their work, such as clinical supervision or reflection. Working in a team is helpful, particularly if there is a mechanism to feed back to other members in the team and/or senior nursing staff.

However, for those community nurses struggling with aspects of caring for patients, occupation health and staff counselling represent further sources of support.

**Carer support**

A key aspect of end-of-life care for community nurses is supporting the carers (Jackson and Dixon, 2012). As death approaches relatives need to be prepared, for example, by being informed about the possibility of a death rattle or Cheyne-Stokes breathing (an abnormal pattern of breathing that often precedes death). At this point it may be appropriate for the community nurse to suggest the family contact a spiritual or religious figure, depending on the patient’s wishes. The family also need to know who to contact when the patient dies, as in most situations this does not necessitate a ‘999’ call.

Community nurses may be involved in certifying death, but they also need to advise regarding registering the death and sources of further help and support in bereavement.

**CONCLUSION**

Community nurses have a pivotal role in coordinating and providing hands-on care (King et al, 2010). Management of patients who are dying at home is a daunting challenge and involves a range of different skills, including ‘people’ skills such as listening and providing psychological support, as well as clinical knowledge about pain and analgesia.

Given the choice, many people prefer to die at home and for the community nurse, communication, symptom management, and supporting the patient and family are key aspects. Community nurses are ideally placed to prepare patients for death, and must ensure that they take responsibility to provide patient-centred, evidence-based care.  

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