Provision of end of life care in the community

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Summary
Many people who are terminally ill would prefer to die at home. Integrated professional working is necessary to enable patients to remain in their homes for end of life care. This article describes how an integrated district nursing team in Lincolnshire provides end of life care to patients in the community. The team uses the Gold Standards Framework and the Liverpool Care Pathway to provide optimum care to patients and their families and carers at the end of life.

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In 1859 a wealthy Liverpool merchant, William Rathbone, employed a private hospital-trained nurse, Mary Robinson, to care for his dying wife. He was so impressed with the nursing care given to his wife that after her death he continued to employ the nurse to care for the people who lived in the poorest areas of Liverpool.

Recognising the benefits of nursing in the home and realising that there was a shortage of trained nurses, he wrote to Florence Nightingale, who advised him to start a training school to prepare nurses to work in people’s homes. After funding a nursing school in Liverpool to train nurses to work in the 18 ‘districts’ of the city, district nursing was born (Queen’s Nursing Institute (QNI) 2008).

In the 150 years since the first district nurse performed palliative care for a patient in the home environment, the provision of end of life care has become increasingly complex (National Audit Office (NAO) 2008). This article describes provision of innovative approaches to end of life care by an integrated district nursing team in Lincolnshire.

Background
Palliative care is defined as an approach that improves the quality of life for patients and their families who are faced with problems associated with life-threatening illness (World Health Organization (WHO) 2009a). This is achieved through prevention and relief of suffering by way of early identification and impeccable assessment, alongside treatments for pain and other problems encompassing physical, psychosocial and spiritual support.

Patients want choice over care at the end of their lives (Department of Health (DH) 2003). Research by the NHS Confederation (2005) found that 56% of terminally ill patients would prefer to die at home, but only 18% actually do. Shortages of district and community nurses mean that terminally ill patients are often denied their preferred place of care and are admitted to hospital unnecessarily (NAO 2008). While most people would prefer to die at home, in reality 58% of deaths occur in NHS hospitals, 17% in care homes, 4% in hospices and 3% elsewhere (DH 2009).

While it is recognised that palliative care is usually delivered by a wide range of professionals (National Council for Hospice and Specialist Palliative Care Services 2002), the primary
healthcare team has a pivotal role in care delivery to patients requiring palliative care at home.

Health care is shifting from hospital to primary care across the health spectrum, from complex disease management to end of life care, giving patients, families and carers preference where possible to be treated at home (DH 2006). This was supported by Lord Darzi in High Quality Care for All (DH 2008a), which sets out the vision for a modern, responsive, high quality service delivered to people nearer to home and aimed at preventing unnecessary hospital admissions (DH 2008a). The Transforming Community Services and World Class Commissioning programme (DH 2009), designed to improve service provision and drive up quality and overall performance in services delivered to local communities, focuses on end of life care as one of the six key core service areas.

The End of Life Care Strategy (DH 2008b), which promotes high quality care for all adults at the end of life, states that most people will spend the majority of their last year of life in the community, with even more able to do so through a reduction in avoidable hospital admissions. Integrated, professional working is essential for patients to remain in their home for end of life care.

The district nurse case manager (DNCM) is often the key worker in the initial holistic assessment of palliative care needs and complex equipment requirements in the home. Referral to specialist colleagues and care providers is undertaken to maximise and co-ordinate care to guarantee delivery of a high quality service. Daniels (1999) suggested that district nurses play an important role in needs assessment and the development of a therapeutic relationship with the patient, and are well placed to liaise across the boundaries of primary and acute services.

Information needs to be shared between formal and informal carers, otherwise mistakes might occur and vast amounts of time could be spent gathering information between professionals and care settings (Cancer Services Collaborative ‘Improvement Partnership’ 2004). District nurses play a vital role in the delivery of end-stage palliative care, especially with interprofessional working and support for caregivers (Hughes 2004).
End of life care provision in Lincolnshire

Pountney (2009) suggested that ‘district nursing is at the centre of 21st century health care’ and still holds the same values and beliefs that inspired district nursing a century and a half ago. The emphasis is now on managing complex health care in the patient’s home through expert assessment and care, and working in close partnership with the patient and his or her family (QNI 2009).

Integrated district nursing teams providing end of life care in Lincolnshire strive to keep people at home. A study by the Audit Commission (1999) found that palliative and terminal care patients took up to 40% of a DCM’s time, despite only making up 8% of the DCM’s caseload. The DH (2000) responded in The NHS Cancer Plan: a Plan for Investment, a Plan for Reform by funding a three-year programme, from 2001 to 2004, to educate district nurses in the principles and practice of palliative care.

One of the tools used in Lincolnshire by district nurses to optimise teamwork is the Gold Standards Framework (GSF) (www.goldstandardsframework.nhs.uk). This was developed for use in primary care across all disease groups of patients with advanced illness. The framework focuses on bringing the best of the advances in hospice care into the community, offering the primary healthcare team the tools to improve the planning of palliative care.

Box 1 outlines the main goals of the GSF, which address the needs of the patient, carers and staff who are delivering the care. Optimal care for patients in their last year of life and support for their carers is achieved in Lincolnshire using a programme that centres around seven components of care provision, which aim to make good care standard for all patients every time (Thomas 2003):

- Communication.
- Co-ordination.
- Control of symptoms.
- Continuity.
- Continued learning.
- Carer support.
- Care of the dying.

These components will be used as a framework for the rest of the article and a patient case study will illustrate how the components are used in clinical practice.

**Communication and co-ordination** Good communication skills are fundamental, particularly in palliative care (Wallace 2001). It is vital that patients and their families’ questions and concerns are listened to and answered in a way that respects their dignity, culture and beliefs. Dunne (2005) stated that, in palliative care, the individual needs of the family should never be overlooked and effective communication by all involved is vital.

Communication and sharing of information between professionals should be centred on the needs and views of the patient. Therefore, all patients, usually in the last six to 12 months of life, are added to an electronic GSF supportive care register. Following discussion between the GP, DCM and Macmillan nurse, patient care is recorded, planned and monitored. This register is maintained by the DCM in the practice and is used to discuss patients at the monthly primary healthcare team meeting.

The aim of the monthly primary healthcare team meeting is to update and discuss advanced planning and proactive care with all relevant members of the team. Proactive care allows the team to anticipate potential problems and plan how to deal with them.

Every patient has a care plan that states his or her preferences and needs. Advance decisions to refuse treatment are an integral part of care planning. The meetings are also used to reflect on any deaths that have occurred. Recording outcomes, such as whether the patient’s preferred place of death was recorded and achieved, provides an opportunity to review and audit the care given, leading to change and development where appropriate.

**Control of symptoms and continuity** The NHS Cancer Plan (DH 2000) states that ‘the care of all dying patients must improve to the level of the best’. To provide the best care possible, patients on the GSF register have their symptoms assessed, discussed, recorded and acted on by members of the multidisciplinary team, and individuals are allocated a named GP and DCM.

Anticipatory prescribing is practised to ensure that there is instant access to drugs that
**Principles of a good death**

- To know when death is coming and to understand what can be expected.
- To be able to retain control of what happens.
- To be afforded dignity and privacy.
- To have control over pain relief and other symptom management.
- To have choice and control over where death occurs (at home or elsewhere).
- To have access to information and expertise as required.
- To have access to hospice care in any location, not only in hospital.
- To have control over who is present at the end of life.
- To be able to issue advance decisions, which ensure wishes are respected.
- To have time to say goodbye and to have control over other aspects of timing.
- To be able to leave when it is time to go, and not to have life prolonged pointlessly.

(Age Health and Care Study Group 1999)

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This is still the framework of choice used throughout Lincolnshire. Treatment should start at the step of the ladder appropriate for the severity of pain experienced by the patient, and doses should be titrated following regular assessment of effectiveness.

Patients with mild pain should be treated with oral non-opioid medications such as paracetamol and aspirin. If pain is not relieved, mild opioids, for example codeine and tramadol, should be used. Step three involves administration of strong opioids (such as morphine), which are often administered subcutaneously using a syringe driver to a patient at the end of life in the community setting. Opioid side effects are considered and, in general, all patients prescribed morphine are also prescribed a laxative. Additional drugs called adjuvants can be used. These could include tricyclic antidepressants or anticonvulsants for neuropathic pain, and steroids for raised intra-cranial pressure or spinal cord compression. It is recommended that drugs should be administered ‘by the clock’ and not ‘on demand’ to ensure freedom from pain.

When patients are added to the GSF register, information including their care plan and prescribed drugs is faxed to the medical out-of-hours service, therefore promoting anticipatory care to reduce crisis and inappropriate admissions to hospital. Patients and carers are given a small green-coloured card and explanatory leaflet with direct contact details for out-of-hours advice with an experienced clinician at any time. This scheme is a county initiative developed jointly between Macmillan and out-of-hours services, which allows the patient to fast-track access to appropriate medical and nursing care by bypassing computer triage and alerting out-of-hours staff that the patient has palliative care needs and requires immediate assessment. The service operates between 6.30pm and 8.00am on weekdays and for 24 hours on Saturdays, Sundays and bank holidays.

**Continued learning and carer support**

Regular GSF meetings are organised by the DNCM with GPs and Macmillan nurses to discuss the patient’s status and to plan and anticipate the needs of the individual and carers. Reflective discussion and analysis follow the death of a patient to review what aspects of the care were good and what possibly could be improved for future work.

Practical and emotional support is offered to families and carers with information about resources that are available to them. Relevant referrals are made by the DNCM for night care from the Marie Curie nursing service to allow carers respite. It is recognised that carers play a vital role in enabling patients to die in their place of
choice and it is acknowledged that they are central to the patient’s care plan. The district nursing team offers carers their own needs assessment with a relevant care plan, which is reviewed and discussed at the GSF meetings. Following the death of a patient, the district nursing team offers bereavement care by visiting carers to ensure continued support.

Care of the dying Patients in the last couple of days of life are cared for following the Liverpool Care Pathway (www.endoflife.nhs.uk/eol/lcp.htm) (Ellershaw and Wilkinson 2003). This is an evidence-based document setting out the appropriate delivery of care to dying patients by focusing on the physical, psychological and spiritual comfort of patients and their families and carers. It dovetails with the GSF to ensure dignity and comfort, and is presented in three sections:

- Initial assessment.
- Ongoing assessment and care.
- Care after death.

Non-essential drugs and inappropriate interventions are stopped. Appropriate oral drugs will be given subcutaneously. The patient’s GP and the multidisciplinary team will make this decision when the individual is unconscious or semi-comatose and is no longer able to swallow medication. Patient details are updated to the out-of-hours service as it is imperative that vital information, such as ‘do not attempt resuscitation’, is communicated to GPs and the ambulance service to avoid inappropriate interventions and admissions to hospital. Drugs are usually administered subcutaneously via a syringe driver, and family and carers are advised what to do as the patient’s condition deteriorates. The DNCM refers the patient to the out-of-hours nursing service to check the medication is dispensing, via the driver, as per GP prescription, and to assess control of the patient’s symptoms to include pain, agitation, nausea and vomiting, dyspnoea and respiratory tract secretions. Symptom control guidelines are attached to the Liverpool Care Pathway and general nursing care is undertaken as appropriate.

The DH (2008b) states that good end of life care should not stop at the point of death. A vital element of a ‘good death’ is that the patient is dealt with in a timely manner for verification and certification of death. The ability of the appropriately trained nurse to confirm inevitable, expected death of a patient and provide aftercare to relatives and carers enables continuity of care at a time of distress and anxiety. However, certification of death must be completed by a medical practitioner.

The following real-life case study illustrates care delivered to a patient in his home by the multidisciplinary team, using the GSF and the Liverpool Care Pathway. All names and identifying features have been altered to maintain the patient’s anonymity.

Case study

Roger was a 73-year-old retired builder who was diagnosed with colorectal carcinoma with lung metastases. He was known to the nurses as they had undertaken flushing of his Hickman line two years previously when he was undergoing chemotherapy. As his disease progressed he attended a city hospital weekly for abdominal paracentesis, but was finding the effort of travelling and waiting for his treatment more exhausting as his health deteriorated. Roger was on the GSF supportive care register and was given a ‘green card’ by the DNCM leading his care for out-of-hours support. His care plan and needs were discussed at the monthly primary healthcare team meetings. Roger’s GP and DNCM were approached by the hospital to discuss the possibility of undertaking ascites drainage at home.

Following insertion of a permanent drainage system under a local anaesthetic in hospital, Roger returned home under the care of the primary healthcare team. Close communication between the community nurses, GPs and Macmillan nurse allowed flexible and timely care to be delivered to Roger when it was appropriate for him. Discussion with Roger and his wife about the fact that he was dying and how the team would support him to stay at home was achieved through honest, open communication.

For the last three months of Roger’s life the nurses visited at least three times a week to assess for re-accumulation of ascites and to observe for abdominal distension and pain. Roger was averaging between four and five litres drainage per week and was well aware when the drainage needed to be undertaken as he would experience a dull, continuous ache across his abdomen. Otherwise he had little discomfort. He would phone the nursing team if extra visits were required to drain the ascitic fluid, thus giving him control of the situation. His wife was offered extra support, but she declined as she had a good family network.

Roger gradually became more jaundiced and was diagnosed with pruritus, which responded to chlorphenamine. He was prescribed protein drinks to compensate for protein loss. Over time, Roger became hypotensive and jaundiced, and had increased peripheral oedema. He was eventually placed on the Liverpool Care Pathway and all non-essential medication was stopped. Roger’s symptoms were well controlled on a regular prescription of diamorphine, midazolam and hyoscine butylbromide administered via a syringe
driver. Nursing support was increased to several visits a day, including visits from the out-of-hours nursing service. Roger died peacefully in his own home in the presence of his family.

Following his death, the care given to Roger was discussed at the next GSF meeting, and in particular the learning opportunities around abdominal paracentesis, as this was the first time it had been undertaken locally in the home setting. The GP visited Roger’s wife at home, and the DNM and Macmillan nurse supported her with follow-up bereavement visits after Roger’s funeral.

**Conclusion**

This article has provided an overview of how the integrated nursing team in Lincolnshire delivers high quality care to patients in the end stages of their disease by using the GSF and Liverpool Care Pathway as methods of assessment and tools to measure symptoms. These pathways enable communication within the multidisciplinary team and integrate national guidelines into clinical practice.

All patients nearing the end of life, regardless of their diagnosis, should be offered the same access to high quality care so that, if they wish, they can choose to die at home. The nurse’s relationship with the patient is a pivotal part of delivering palliative and end of life care at home. A case study outlined an example of care delivery and the provision of support to a patient who requested abdominal paracentesis in his home to avoid numerous visits to an acute setting for ascites drainage.

Effective communication is central to good patient care to support individuals with their needs and choices at the end of life. The 150th anniversary of district nursing sees integrated nursing teams providing high quality palliative and end-stage care to patients in the community setting in partnership with GPs, specialist practitioners, formal and informal carers, and people in the voluntary sector.

End of life care is not just about managing pain and other physical symptoms, but includes support to deal with emotional, social and spiritual needs, and care following bereavement. When death is imminent there is no second chance to improve quality of care for the patient, therefore it is imperative that robust assessment and care co-ordination is in place to enable a dignified death in the patient’s chosen location NS