Ensuring patient choices about dignity and place of death are respected at the end of life

Patients’ palliative care preferences should be respected, but many people still do not die at home. This article examines how services must adapt to allow this to happen.

INTRODUCTION
Although only 25% of palliative care is concerned with controlling physical symptoms (Lloyd-Williams, 2003), caring for the dying has traditionally focused on physical aspects of care.

Research on improving end of life care shows that patient distress is alleviated through psychosocial interventions for one third to half of those with cancer (Carlson and Bultz, 2004). Although the evidence shows that patients make fewer visits to their GP after psychological interventions (Chiles et al, 2006), this aspect of care is not emphasised in practice (Cunningham, 2000).

This article offers a critical review of the effect on patient outcomes of meeting their needs at the end of life, and includes those with long term conditions as well as cancer.

PSYCHOSOCIAL CARE
Alleviating distress when patients no longer feel connected with the world and are angry that their body has failed them can be challenging for healthcare professionals. Patients may find it difficult to discuss threats to their personhood and it is only through effective communication and interpersonal skills that nurses can address these issues (Lloyd-Williams, 2003).

Evidence suggests that change in end of life care will only happen if patients are allowed to prepare for and face death by expressing fears, hopes and desires (Neuberger, 2004). Some management strategies prevent this; for example, medication to alleviate anxiety may also block fear, so the source of fear or anxiety will not be understood and the cause will not be addressed. Patients have reasons to be afraid and allowing them to express their anxiety is crucial (Cannaerts et al, 2004).

The importance of psychosocial care should never be underestimated and psychological management should be considered equally important as physical management across primary, acute and tertiary care (Lloyd-Williams, 2003).

All healthcare professionals need to be able to understand and recognise patients with complex psychosocial needs and make comprehensive assessments of the distressing issues that patients may face.

DYING AT HOME
National Institute for Health and Clinical Excellence (2004) guidelines recognise the importance of addressing patients’ needs and preferences. The National Preferred Priorities for Care Review Team’s (2007) Preferred Priorities for Care also emphasised this. It encourages sharing of information and good communication, documenting patients’ and carers’ choice of care. It allows multidisciplinary teams and other services to plan and reduce inappropriate admissions and interventions, and patients to plan ahead and think about their values and beliefs.

However, Preferred Priorities for Care (NPPCRT, 2007) acknowledges that resources may not be available to meet the needs expressed by patients.

Carers may become tired or ill and informal carers may need more support to understand the complexity of looking after patients who are dying (Hudson et al, 2005). Other resources should therefore be in place, especially for those who have no family or friends, or live in a deprived area where hospital admission is highly likely due...
to smoking, poor diet and alcohol related disease (Welch et al, 2010).

The title, Preferred Priorities for Care (NPPCRT, 2007) reflects the importance of patients’ preferences and recognises that place of death is only one of the decisions to be made by those facing the end of life.

While the 2004 version of Preferred Place of Care placed more emphasis on the patient, that is, where care is provided, the new one places more emphasis on the care provider and prioritising how care is given. In reality, the key difference is that the later version puts a greater emphasis on supporting people who choose to die at home, which has resource implications, versus health professionals setting priorities and selecting the level of care provided.

More patients are dying with multiple organ failure, blood dyscrasias and metabolic abnormalities and many choose to die at home (O’Mahony et al, 2000).

Although recent guidance stresses the importance of patients’ preferences, there are often situations where families expect district nurses and other health professionals to collude with them and withhold information from patients to affect the outcome of where they die (see Box 1).

One problem facing patients and families is that it is difficult to guarantee 24 hour care at home because of lack of funding and infrastructure to support home care services. Providing 24 hour care is expensive but there is evidence that by focusing on the behavioural, clinical and government support for the Gold Standards Framework and the Liverpool Care Pathway. However, patients’ needs are not being met because of a lack of care planning and an increase in the ageing population (Gomes and Higginson, 2006). Despite a rise in palliative care services, the proportion of people dying at home has not increased (Gomes et al, 2008). Inequalities in terms of hospital and home deaths are still present and research shows a range of factors are strongly associated with home death, including low functional status and family support (Gomes and Higginson, 2006).

Studies have shown, however, that people aged over 70 are less likely to die at home than those in their 50s or 60s (Gomes et al, 2008). This shows that older people are not dying in their preferred place of care and their psychosocial needs are not being met.

**Commissioning**

The National End of Life Care Programme (www.endoflife-care.nhs.uk/eslc) aims to achieve world class commissioning for end of life care. The goal is to explore and debate the opportunities and future challenges for commissioning of end of life services.

A lack of planning, listening to, and acting on patients’ needs is still causing ongoing crisis admissions to hospitals (O’Brien and Jack, 2009). There are examples of patients being poorly supervised in side rooms to avoid their being in busy areas.

Dying patients may be seen as bed blockers in wards but discharge is difficult because carers feel unable to cope at home. Such a situation can compromise patients’ dignity and lead to inadequate care for patients who are vulnerable and dying.

Major changes are needed to support people dying at home, as by 2012 the number of deaths is expected to rise by 17% due to an increase in ageing, deaths and the number of older people living alone (Gomes et al, 2008).

**IMPLICATIONS FOR SERVICES**

District nurses spend much of their time caring for patients with psychosocial and physical problems, the acutely ill and those in the terminal phase of illness. A key element of practice is to support patients who are dying, enabling them to die pain free, both physically and psychologically.

The aim is to give informal carers the opportunity to care in a positive way when death of their loved one is imminent.

In modern culture, the preferred place of death is usually at home (Thomas et al, 2004). However, we need to provide a service for patients who have no family or friends but still wish to die at home, as they often fear dying alone (Gott et al, 2004).

However, it is not always possible for patients to have a home death and some are best cared for in a hospital or hospice. Some patients still feel there is a stigma surrounding hospices, seeing them as places where people go “just to die”. It can be difficult for district nurses to explain that this is the best place of care, especially for those who have lived alone for years, when their preferred place of care is their home.

Patients suffering from a long term terminal illness or who need acute, complex treatment – such as those with cerebral vascular disease or a haematological malignancy – are more likely to be hospitalised.

District nurses also encounter situations where expert resources are lacking. There is often a need to monitor and evaluate patients’ symptoms and anxiety over 24 hours, and those with family or friends can sometimes become irritable and tired. Relieving pain and symptoms can be difficult when there are situations hasten death, which may cause distress to inexperienced district nurses.

Further research from diverse cultures is needed on end of life care to ensure good deaths for all patients who are terminally ill. Palliative care staff face many dilemmas in everyday practice, as race and cultural backgrounds can influence people’s

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**BOX 1. CASE STUDY**

District nurses were visiting Mrs Jane Black, who had end stage metastatic cancer, to provide symptom control, management and support. Mrs Black’s wish was to die at home, but her son Paul wanted her to go into a hospice as he felt he could not cope. This difficult situation posed an ethical dilemma for the nurses as the interests of the son were different from those of the patient and he wanted them to withhold this information. Mrs Black’s condition deteriorated and it became evident that she needed 24 hour care. This situation was distressing for the district nurses, who tried to encourage Mr Black to discuss his fears and concerns with his mother, who eventually went on to die peacefully in a hospice.

This is an example of the everyday dilemmas that district nurses face, when patients’ preferred place of care changes due to the priorities of carers involved or other factors such as a crisis hospital admission. *Names have been changed.*

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**A NEED FOR CHANGE**

The NHS Cancer Plan (Department of Health, 2000) recognised that “the care of the dying must be raised to the level of the best”. The Gold Standards Framework (www.goldstandardsframework.nhs.uk), which has been part of the NHS End of Life Care Programme for four years, emphasised advanced care planning where organised care responds to patients’ needs and the end of life care agreed with them.

The World Health Organization developed international recommendations on end of life care planning to support patient choice (Davies and Higginson, 2004). There is also clinical and government support for the Gold Standards Framework and the Liverpool Care Pathway.
principles and morality. Health professionals need more education to understand discrimination and inequality in palliative care (Peckover and Chidlaw, 2007). Planning for end of life care needs to start openly and honestly, given that primary care specialists have the potential and ability to care for dying patients at home. GPs are ideally placed to identify patients at diagnosis who are likely to require end of life care; this presents an opportunity to discuss patient centred supportive care within primary care with district nurse and specialist nurse input.

Research needs to examine why home deaths have declined; more quantitative data needs to be put together. Geographically, data on the influences of bed availability in hospitals and hospices on the number of “institutionalised deaths” needs to be collected, as well as the experiences of district nurses, GPs and Marie Curie nurses. Hospital episode statistics show where patients with different cancer diagnoses are admitted and the length of stay during the last six months of life. The rate at which patients die following admission should be studied. Qualitative studies should focus on the changes and different patterns of healthcare. These studies may include information about the dying process, such as death predictability and behavioural choices. Social background also needs to be considered. Telehealth advances will make it possible to monitor patients and alter treatment remotely. Research is exploring how medical services in the home can be supported with information and communication technology. This may help provide 24 hour services to dying patients at home and reassure relatives that their condition is monitored and assessed without delays in health professionals getting to the home (Fergus et al, 2009).

CONCLUSION
Death is inevitable; it is not defeat and the journey to the end should be peaceful. The desire to die at home should always be respected as far as possible. Health professionals can help ensure a good death for all patients through careful planning and listening to them throughout their journey. However, complications arise when those dying have no support from informal carers; this may mean formal care is needed. The only way to resolve many of issues discussed is to provide 24 hour care. This is extremely challenging, but we must strive to provide a novel approach where technology and health come together in the home.

REFERENCES