The principles behind end of life care and the implications for patients’ skin

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End of life care became the focus of media attention in 2013 when the Liverpool Care Pathway was found to be not fit for purpose. This article looks at the policy background to end of life care in the UK, as well as the current state of provision, from a community nursing perspective. It also focuses on pressure ulceration, a key complication for patients at the end of life, offering advice on how to approach skin care for this patient group. Finally, the author examines the implications for treatment of mental capacity legislation, and how concepts such as ‘advanced decisions’ and ethics affect nurses trying to treat patients at the end of life.

KEYWORDS:
End of life care ■ Policy ■ Pressure ulcers ■ Ethics

In wider society death is often perceived as a difficult subject and is avoided rather than discussed. Unfortunately, this can also be true of healthcare settings and means that improvements in care and quality of services for patients at the end of life can vary greatly in different areas (Ward, 2010).

During the early 20th century, death took place mostly at home and the dying and sick were cared for by family members (Dickenson et al, 2000). The second half of the 20th century saw the emergence of palliative care, with hospice care in the UK contributing greatly to clinicians thinking about death, dying and bereavement (Thomas, 2003).

Fast forward to the present and the National Audit Office (2008) recently identified that 56–74% of the population wish to die at home, while 40% of hospital deaths occur in patients who have no medical reason to be there (Bowers, 2010).

Similarly, research has found that despite the majority of end of life patients preferring not to die in hospital, 58% still do (Bowers, 2010). It has been suggested that this is because people often medicalise or institutionalise dying, rather than accepting death in homes and communities, where most of us would choose to die (Sentamu, 2012).

Macmillan Cancer Support (2010) identifies that despite the government’s End of Life Care Strategy (Department of Health [DH], 2008), which called for ‘around-the-clock’ community care for patients to remain at home, only 56% of primary care trusts in England actually offer this service. Devane (2012) highlights that family and carers are often left with no choice other than to call the emergency services when incidents occur at home.

When around-the-clock community care is provided it has been shown to improve the quality of patients’ experience and is effective in reducing unnecessary hospital admissions (Macmillan Cancer Support, 2010). The DH white paper (2012), Caring for our Future: reforming care and support, focuses on achieving more consistency in patients’ access to services around the country. Greater consistency of service provision would give patients more choice about their care and improve integration of services (DH, 2012).

As highlighted above, end of life patients are often admitted to hospital rather than being provided with services that support them to die at home — the DH (2008) support this, with statistics stating that only 18% of end of life patients dye at home.

Despite this, Agar et al (2008) and McCall and Rice (2005) argue that as death approaches, patients often change their mind about their preferred place of death and home becomes less attractive due to a desire not to burden relatives or be unable to control symptoms.

However, according to the DH (2009a), if care was planned, coordinated and individualised, more end of life patients would be able to die in their location of choice.

BACKGROUND

The word palliative originates from the Latin word ‘pallium’, meaning cloak or shield (Old and Swagerty, 2007). The implementation of hospice care and the palliative care movement radically changed...
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professional practice and perceptions around the care of dying people all over the world (Clarke and Seymour, 1999; Thomas, 2003).

Founded in 1967, St Christopher’s Hospice in London was opened in recognition that the care needs of dying people were not being met (Kinghorn and Gamlin, 2003) — indeed, when the hospice began receiving patients, care of the dying was still overlooked by the NHS (Clarke and Seymour, 1999).

Palliative care itself was developed as part of the hospice movement (Cooley, 2009), although initially it was provided predominantly for individuals with cancer. Hallenbeck (2003) criticised hospice care as being too narrow and focused on providing care for a select group of individuals, which excluded those with non-malignant illnesses.

By the 1990s, interest in providing palliative care for all individuals, regardless of their illness had began to grow (Clark and Seymour, 1999). The Standing Medical Advisory Committee (SMAC) and Standing Nursing and Midwifery Advisory Committee (SNMAC) (1992) recommended that a better attempt should be made to extend palliative services to patients who did not have a cancer diagnosis, with care being provided on an individual basis, rather than depending on specialised services such as hospices.

Providing care for end of life patients and their relatives regardless of diagnosis has become a priority in the UK (DH, 2000a; 2000b; 2001; 2003; 2008; 2009a; 2009b), and the development of medicines that can improve patients’ quality of life has undoubtedly contributed to the recognition of palliative care as a nursing specialty (Becker, 2009). Nonetheless, providing good quality care remains a major challenge (Royal College of Nurses [RCN], 2002; Costello, 2006).

MODERN PALLIATIVE CARE

Palliative care is now defined as the care of patients who have a life-limiting illness, which is delivered by a multiprofessional team when the illness no longer responds to life-prolonging or curative treatment (Twycross, 2008).

Payne et al’s (2008) definition of palliative care includes the patient’s quality of life as well as physical, psychological and spiritual elements. However, Beauchamp and Childress (1994) suggest broad concepts such as quality of life can be misleading and need careful analysis.

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Assessment is a critical first step in ensuring that services meet patients’ needs. However, unnecessary repeat assessments completed by different clinicians are of little benefit to end of life patients (National Institute of Health and Clinical Excellence [NICE], 2004).

Randall and Downie (2006) argue that clinicians should concentrate on completing the required documentation instead of listening to the patients’ needs, fears and wishes at the end of life. However, other sources all recommend that clinicians need to work together in a supportive and professional way to achieve better communication and standards of care for end of life patients (The Kings Fund, 2010; DH, 2008; 2009a; 2009b; NICE, 2004).

Palliative care should be delivered by a range of professionals and the UK government’s current health policies are playing a pivotal role in shifting services from hospital to the community setting, including end of life at home (DH, 2006; Henry and Hayes, 2010). This is supported by High Quality Care for All (Darzi, 2008), which aims to prevent unnecessary hospital admissions and provide services nearer to patient’s homes.

In 2005, the End of Life Care Programme (NHS Confederation, 2005) was set up to promote good practice for end of life patients. As part of the programme, the preferred place of care (PPC) document asked patients to write down their end of life care priorities, a task aimed at helping clinicians understand what was important to patients when planning their care (Storey et al, 2003). Similarly, the Gold Standard Framework (www.goldstandardsframework.org.uk) focused on quality, management and the establishment of care for patients with any end-stage illness in any setting and is aimed at patients receiving the care they want in their chosen environment (Thomas, 2003).

In the past, the Liverpool Care Pathway (LCP) was recommended in the last days of life and concentrated on the physical, psychological and spiritual comfort of patients (Ellershaw and Wilkinson, 2003). However, recently, the LCP sustained substantial criticism from the media, professional bodies and relatives of patients. An independent review of the pathway was conducted in 2013 and the review panel strongly recommended that the LCP be replaced with an end of life care plan (Independent Review of the Liverpool Care Pathway, 2013).

End of life care plans should be specific to the patient’s individual needs and preferences and backed up by condition-specific good practice guidance. Individuals with an end of life care plan can expect their care to be pre-planned, coordinated, ethical and equitable in terms of preferences and personal beliefs, thereby helping to ensure good end of life care (DH, 2011).

Similarly, the End of Life Care Strategy (DH, 2008) promoted high-quality care for all patients at the end of life. The strategy outlined how patients should be cared for to ensure a good death, with the overall intention being to provide:
- Better management of services
- Accessibility of palliative care
- More responsive around-the-clock services
- Training for clinicians to better enable patients to experience their chosen type of death (Torjesen, 2008).
The development of pressure ulcers in end of life patients is not a modern phenomenon. Charcot (1877) described a butterfly shaped pressure ulcer over the sacrum in patients in their final days of life. More recently, Kennedy (1989) defined the Kennedy terminal ulcer — a butterfly, pear- or horseshoe-shaped pressure ulcer developed on the coccyx or sacrum by some end of life patients.

Pressure ulcers in end of life patients develop in part due to the skin changes that accompany ageing, as well as disease progression and/or:

- Physiologic changes that occur as a result of the dying process may affect the skin and soft tissues
- or where patients choose not to participate in prevention strategies (Stephen-Haynes, 2012). Wilson (2012) has even stated that pressure damage at the end of life is inevitable. However, the DH (2010a,b,c) and the European Pressure Ulcer Advisory Panel/National Pressure Ulcer Advisory Panel (EPUAP/NPUAP, 2009) do not focus on skin changes at the end of life.

NHS settings have to report and investigate all category three and four pressure ulcers as serious incidents (Beldon, 2011a) and Chamanga (2011) has stated that most, if not all, pressure ulcers can be prevented. However, Wilson (2012) and Beldon (2010) have agreed that the complex aetiology of pressure damage and the multiple pathologies experienced by end of life patients — such as heart disease, cancers, diabetes, chronic obstructive pulmonary disease (COPD) to name but a few — make a certain amount of pressure damage unavoidable, even if the most comprehensive prevention strategies are in place.

In 2009 a consensus statement on skin changes at life’s end (SCALE) (Sibbald et al, 2009) stated that:

‘Physiologic changes that occur as a result of the dying process may affect the skin and soft tissues

and may manifest as observable changes in skin colour, turgor, or integrity, or as subjective symptoms such as localised pain. These changes can be unavoidable and may occur with the application of appropriate interventions that meet or exceed the standards of care.’

The SCALE document provides guidance for nurses on the care of patient’s skin at the end of life setting out 10 statements that incorporate the best evidence-based practice (Beldon, 2011b). These statements identify that patients require regular skin assessments, planned care — which is in accordance with the patient’s symptoms and wishes — and education of patients and relatives (Sibbald et al, 2009).

Due to lack of research, experts are unable to explicitly endorse one specific risk assessment tool for all clinical areas (EPUAP/NPUAP, 2009), and there are only a few risk assessments validated for use within palliative care. However, Beldon (2010) and Sibbald et al (2009) argue that a risk assessment tool specifically for end of life patients would help with the correct identification of risk and the accurate use of equipment.

Education
At the end of life, education of patients, relatives and healthcare professionals is of the utmost importance (DH, 2008). Education helps people to understand that the patient’s skin may be compromised and will have little tolerance to minimal pressure (Sibbald et al, 2009). Education also helps to ensure that assessment and management of the skin in end of life patients is sensitively dealt with, thus reducing complaints and litigation (Guy, 2012).

Appropriate equipment, repositioning, skin care and nutrition should be provided, but it must be recognised that due to comorbidities and organ failure, end of life patients may still develop pressure damage. Some nurses see the development of pressure damage as a failure and fear litigation or complaints. However, communication and education of patients, relatives and other
Patients also have the right to refuse or be non-concordant with treatment (NMC, 2008). The Mental Capacity Act (2005), presumes all adults to have adequate capacity to decide on their own medical treatment unless there is sufficient evidence to suggest otherwise. When patients have full physical and mental capacity they can refuse to be repositioned with assistance or independently (Wilson, 2012).

It is vital, therefore, for nurses to communicate with patients, relatives and carers to ensure that they are aware how any refusal of treatment may impact on pressure ulcer development at the end of life (Beldon, 2011a). Devlin and McIlfatrick (2010) support this, but stress that if communication is poor the patient and family could potentially refuse treatment.

If patients lack mental capacity and resist treatment, this can be challenging for nurses (Stephen-Haynes, 2012), although these patients should not be considered non-concordant as they do not have the capacity to understand the possible outcomes of their actions (Guy, 2012).

The Mental Capacity Act (2005) recommends that patients — with or without capacity — should be regularly given the opportunity to change their decision and agree to a treatment plan. Any instructions or notable events — such as the patient’s consent or refusal of treatment; any physical position the patient will or will not tolerate; any previous attempts to reposition the patient; and any preventative care offered by the healthcare team — should all be documented in the patient’s medical notes to help guarantee that other staff and carers are aware of what treatment has taken place or is required (NMC, 2009; Wilson, 2012).

Patients who are concerned about having a lack of capacity in the future, for example those diagnosed with dementia, and who fear inappropriate decisions being made on their behalf can arrange for a legally binding ‘advance decision’ to be drawn up, which will be recognised by the Mental Capacity Act (2005).

These advanced decisions allow patients to refuse treatment if they are no longer able to communicate this refusal (Dignity in Dying, 2012). If patients have an advanced decision requiring that they not be repositioned at the end of life, for instance, clinicians are ethically bound by this and legal action can be taken against any clinician who

End of life care has received so much publicity in recent months and has, therefore, been at the forefront of the minds of healthcare professionals and the general public.

This paper highlights the key issues that are important in the field of end of life care, as well adding a unique and often ignored phenomenon — skin care. This is an essential part of end of life care, however, nurses too often focus on issues around pain control, constipation and sedation (although these are also important issues and should not be neglected). Providing good skin care and pressure care is a fundamental requirement to which nurses contribute a great deal.

I welcome this paper as an important look at an under-regarded area of clinical practice.
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Within tissue viability, end of life patient care can result in a complex ethical dilemma, which is difficult to resolve (Robbins and Moscrop, 1995), as nurses may feel that skin damage needs to be treated, whereas the patient may prefer to be comfortable until the end of their life, irrespective of any healing potential.

Webb (2005) states that ethics are not simply a matter of opinion, but require rational and reasoned thinking in order to propose possible solutions. Worthington (2005) goes on to suggest that ethical dilemmas involve assessing treatment risks against uncertain benefits, for instance, and being able to balance moral values.

The principles of beneficence (essentially ‘doing good’) and non-maleficence (minimising harm), are the main ethical principals for nurses to consider within tissue viability, especially when advising on repositioning end of life patients (Twycross, 2008).

However, the SCALE document (Sibbald et al, 2009) states that, regardless of repositioning, pressure damage in a patient at the end of life is inevitable, making it difficult to prevent harm (non-maleficence) or do good (beneficence). Nevertheless, Worthington (2005) adds that ethics have an important role to play in planning, decision-making and care for end of life patients.

CONCLUSION

While skin deterioration at the end of life may be normal, this does not mean that it should simply be accepted by nurses (Beldon, 2011b).

For all kinds of clinicians, including community nurses, this can be frustrating when there is a responsibility to identify and report pressure ulcers, as well as a potential financial penalty for not doing so (National Patient Safety Agency [NPSA], 2010a, 2010b).

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Against this backdrop, it is essential that community nurses endeavour to maintain their knowledge of end of life issues, and continue to communicate with patients, carers and family at all points of the patient’s journey to the end of life.

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