Keywords Nursing principles/End-of-life care/Confident palliative nursing

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In this article...

- Why nurses play a pivotal role in end-of-life care
- A set of principles a nurse or nursing team can adopt to ensure high-quality care
- How nurses can improve people's experience and outcomes regardless of setting

Key principles of nursing for people facing end of life or loss

Key points

More people than ever are living into late old age, many with multiple morbidities

People want more choice and involvement in their treatment and care decision making for end of life

Nursing is vital in its contribution to high-quality palliative and end-of-life care

Nurses will have a central role in palliative care if they are confident of how they can best support people who are dying or grieving

Clear principles for palliative care nursing can help nurses understand the multiple and contemporary demands for care

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Abstract This article, the first in a series on palliative and end-of-life care, describes key principles that underpin high-quality nursing care for people who are approaching the end of their lives and support those close to them. In a changing landscape of death and dying, the UK health system faces new challenges and opportunities. We highlight the crucial role nurses play in providing palliative and end-of-life care in a range of settings, and offer a set of principles to support their practice. These principles are applicable regardless of nurse seniority, level of expertise, care setting and the patient groups with whom they work.

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The picture of end of life is changing in the UK and beyond, yielding new opportunities and challenges for nurses and others who remain keen to deliver good care and want to shape their efforts accordingly (St Christopher's, nd; Etkind et al, 2017). Bao et al (2019) have highlighted the growing numbers of people who live into late old age, many with multiple comorbidities, including dementia.

Many people living with life-threatening conditions seek to be more independent in the course of their illness and to exercise greater control in the management of their condition – they want the opportunity to influence decisions about:

- Their place of care;
- Who supports them;
- How active they wish their care to be (Choice in End of Life Care Programme Board, 2015).

The recent Covid-19 pandemic has increased awareness of death and dying, and encouraged discussion on the part of the public, forcing additional shifts on how professionals design and deliver palliative and end-of-life care (Islam et al, 2021).

Defining palliative care

This article reflects this reality and defines palliative care in its broadest context, as described in Box 1. It offers an approach for nurses that enables them to enact their pivotal position in the delivery of care for people who are dying or bereaved.

The continuum of palliative and end-of-life care

The invitation for all nurses to adopt the principles we propose is reflective of a continuum of care, historically defined as spanning specialist or generalist input, as noted in the National End of Life Care Programme's (2011) *Route to Success*.

The notion of specialist care has often been linked to an expertise gained through dedicated work with people nearing the end of life (for example, those working in hospice and palliative care teams). Patients with the most complex, or multiple, problems are likely to benefit from this expertise. The National End of Life Care Programme (2011) also referred to the range of registered nurses working at preceptor, staff nurse, specialist clinical nurse and

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Box 1. Palliative care – what it is and what it is not

What it is

- It affirms life and regards dying as a normal process, and seeks to ensure all close to the person are acknowledged and included in this phase of care
- It integrates the human experience of loss, grief and bereavement as core to its ethos
- It is relational and person centred, and care is informed by the wishes and goals of those for whom health professionals care – for example, in terms of symptom management, feeling safe and understanding what is happening
- It offers a support system to help patients live as actively as possible until death, with attention to their personal goals – which extend beyond clinical needs

What it is not

- It is not solely provided by hospices: good end-of-life care can be provided in any care setting with professionals and others working together to meet the changing needs and wishes of the person in their care
- It does not replace treatment; rather it complements it by providing symptom management, emotional support and advance care planning in a timely way
- It does not provide euthanasia or assisted suicide. It focuses on enhancing the patient's quality of life and alleviating suffering, but does not involve any interventions that intentionally end a person's life

> *"How we care for the dying is a litmus test of a good health system as well as a responsible society"*

consultant nurse levels as "specialists" across the NHS and voluntary sector.

In addition, end-of-life care is increasingly the domain of registered nurses working in care homes, primary care, and other settings, particularly those dedicated to the care of older people. Reimer-Kirkham et al (2016) observed how such nurses are ideally placed to integrate a palliative care approach to their care. They will often be expert also in the establishment of strong relationships with those for whom they care, and the delivery of compassionate, kind and warm care, known to be invaluable for those facing end of life (Johnston et al, 2015). These characteristics often exist alongside other expertise, such as the care of people with dementia or frailty, which, as noted by Cagle et al (2017), is increasingly important in today's context.

For many patients, high-quality interpersonal interaction and continuity, alongside basic symptom management skills, is more than sufficient to meet their needs and ongoing referral to more specialist services is unnecessary. The patients, notably, place great value on the relational aspect afforded by continuity of known care givers, as observed by Haggerty et al (2013).

Our article, we suggest, has relevance across this continuum of expertise.

How nurses improve quality of life for the dying

When the principles we propose are enacted, the nurse and their team can expect to make a positive difference to the experience of the patient who is dying, their family, carers and anyone else close to the patient. Consistent with well-known definitions of palliative care, for example those developed by the World Health Organization (2020), and related UK national policy described earlier, the primary goal of good end-of-life care is about improving or maintaining the quality of life of the individual, despite being unable to reverse or cure an advancing and life-threatening condition.

What constitutes a good quality of life will vary from person to person, and will reflect their beliefs, values and goals, in addition to their care needs. These needs will vary from the most fundamental, for example, feeling safe, to the opportunity to be creative and to contribute to other people's lives despite debilitating illness.

Sadly, despite effort on the part of health and social care professionals and others, the quality of end of life remains poor for too many people in the UK and beyond, as noted by the Department of Health (2016) and Knaul et al (2018). Experience, safety and outcomes vary widely, with limited choice for the individual and those close to them (Choice in End of Life Care Programme Board, 2015).

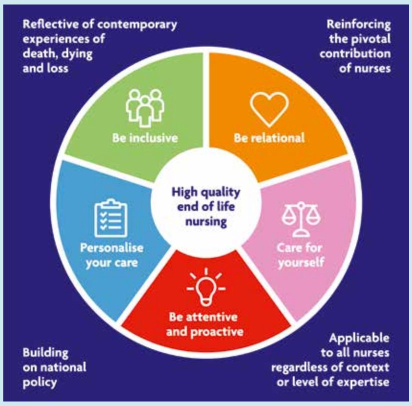
The degree to which a nurse and their team can enable someone to continue to live well – to experience good outcomes even in the face of death – will depend on many factors including time, access to specialist advice (within and beyond palliative care), and the opportunity for creative and autonomous practice in a risk-confident culture. Even so, the principles described next offer some guidance about where a nurse should focus effort, regardless of how stretched and challenging the context of care.

Introducing the principles of high-quality care

The focus on principles is based on a belief that principles form an important foundation for a system of reasoning and behaviours. They are at the heart of ethical decision making and how individual clinicians and their teams respond to the needs and aspiration of those who seek their care. They allow the development of shared intentions, which bring coherence in scenarios that are often uncertain and complex in nature.

The principles proposed are relevant for any nurse interested to deliver high-quality palliative care. They are relevant regardless of where the nurse works, and we encourage their enactment in any setting where people are dying. They are applicable in care homes, in supported housing and in prisons. They have relevance in primary and secondary care, in emergency departments, intensive care units and surgical wards, as well as areas dedicated to end-of-life care such as hospices.

Fig 1. **The five principles**



End-of-life care has never been the sole remit of hospices and is increasingly less so. Indeed, less than half (47%) of those who might benefit from expert end-of-life care receive support directly from a hospice service (Caper, 2017).

Fig 1, created by the authors, seeks to conceptualise the five principles and their context. It identifies factors that shape the principles, and, in turn, how the principles influence the environment in which nurses work.

Five principles

1. Seek to be inclusive

The nurse who is inclusive in such care is active in identifying people who are dying and broad in their appreciation of who might need help at the end of life. Historically, the very best of palliative or end-of-life care focused on people who were dying of cancer. Now there is a much greater appreciation of a wide range of conditions for which a palliative approach could be of help and acknowledgement of the value of palliative interventions early in someone's advancing illness, even if they continue to receive treatments or live with a condition that is chronic in nature.

Being inclusive means extending care to individuals beyond the patient. The words of the poet John Donne in his *Devotions upon Emergent Occasions*, "no man is an island" (Donne, 1959, originally published in 1624), has particular resonance for nurses who want to deliver high-quality end-of-life care.

Patients will usually enjoy important connections with family members, carers, friends and neighbours, and these individuals require attention as they witness someone close to them in the last stages of life and anticipate life without them. The dying person will often have concerns for such loved ones and would want to ensure they too are cared for (Choice in End of Life Care Programme Board, 2015).

Dame Cicley Saunders, founder of the modern hospice movement, placed high value on a positive ending of someone's life to enable those remaining to survive their bereavement and move on – clearly articulated in her observation, "how people die remains in the memory of those who live on" and is enshrined as the strapline for national strategy on end-of-life care (Department of Health, 2008).

Policy, as well as practice, confirms the highly personalised nature of dying (Wee et al, 2021). In responding, the nurse must give priority to conversations about what is important to the person who is dying and those close to them. Being inclusive in this respect means attending to what is uniquely of value to them and the way they live their life. It acknowledges their personal values and beliefs, their culture, sense of identity, history and other contributing factors that give rise to their sense of who they are. Nothing, in being inclusive, can be ignored in this respect.

> *"Nurses have a unique role in end-of-life care, enhanced through rigorous application of key principles"*

2. Be relational

One of the greatest risks faced by nurses today is an unconscious slide from relationship-centred care to that which is transactional in nature. Many of the stresses in contemporary healthcare can unwittingly encourage transactional care, for example, unrelenting demand on individual nurses or their teams and repeated calls for efficiency, increasing regulation and bureaucratisation, reinforced by solutions such as electronic patient notes, pre-prepared care plans and similar. Paradoxically, while such tools are designed to reassure all involved of high quality, they may also serve to erode relationships – identified as the all-important context for so many activities and functions in healthcare (Beach et al, 2006).

Too often we can lose sight of dying as a relational and spiritual process rather than simply a physiological event (Samarasekera, 2022). Being relational is key to enacting the art of nursing as opposed to its science. A senior nurse reflecting on a lifetime career in end-of-life care argues that, in an increasingly medicalised approach to care, the art of nursing, encompassed in the Asklepian tradition of healing and acceptance of mortality in ancient Greek medicine, is at risk of being lost (Horton, 2021). A call is made to nurses interested to improve the experience and outcomes of people who are dying to practice an approach in which the art and science of nursing care are enacted concurrently (Horton, 2021).

Relationship-centred care – a term adopted by both academics and practising nurses – is vital to good end-of-life care (Beach et al, 2006). It gives attention to someone's personhood, and it calls for emotional presence on the part of the practitioner; its reciprocal and personal nature allows authentic connection, enhanced processes and outcomes of care, mutual benefits between nurse and those for whom they care, and honesty within the relationship (Beach et al, 2006).

Dame Cicely wrote convincingly to nurses of the need for such an approach. In an article in *Nursing Times* entitled 'Should a patient know?', she wrote of the importance of truth and trust in the patient-clinician relationship, of courtesy and kindness, and even of love defined as "not sentimentality but compassion and understanding" (Saunders, 1959). Her answer to the question of whether a patient should know their prognosis is a yes in the main. Those sensitive yet vital conversations are a key element of nursing for people approaching the end of life in contemporary healthcare, which are possible only when the nurse is in a relationship with the person.

3. Personalise the care you offer

The notion of personalised care is currently often linked to *The NHS Long Term Plan* published five years ago (NHS England, 2019). It calls for attention to needs beyond those that are physical in nature – spanning emotional, social, financial, spiritual and other areas of concern identified by the patient and other individuals close to them. It is about balancing nurse-delivered care alongside enabling the person, who is dying or those close to them, to support themselves to the degree to which they are able and wish to.

Johnston et al (2015) describe the value of positing the question "what do I need to know about you as a person to take the best care of you that I can?" as key to delivering person-centred care and that which promotes a sense of dignity. Also, the opportunity for self-care is not to be underestimated, even at the end of life. We see this intention to remain independent and to have agency as a positive ambition, not least because the literature confirms a strong relationship between autonomy, control and a sense of dignity, as reported by Rodríguez-Prat et al (2016).

4. Be attentive and proactive in your approach

For the person who is dying, the trajectory of illness is often uncertain and can rapidly change – an experience that is even more likely when people die with frailty and other chronic conditions (Skilbeck et al, 2018).

In response to this, high-quality nursing practice anticipates and prepares for emerging needs on the part of the patient and those close to them ahead of them becoming apparent. Such an approach draws in the patient, family and carers, allowing plans for care to be made in advance, reflective of their priorities and preferences – a process often described as advance care planning.

At its best, nurses will negotiate with patients and those around them the part that each of them will play in the care required; then they will provide training and support for others to contribute as they wish. This activity may well call for input from a variety of professionals beyond the nurse, sometimes across organisational boundaries.

Observant care today will focus on people's symptoms and efforts to control them; it will consider people's mental capacity and the degree to which they can make plans and decisions for themselves. It will also focus on people's levels of independence, their ability to perform aspects of daily living, and other nursing concerns related to tissue viability, nutrition and similar. These aspects of care will be covered later in the series.

5. Care for yourself

End-of-life care is rarely without emotional impact for nurses and others who connect with the person who is dying and those around them who face loss (Goodrich et al, 2015). The nurse will be witness to a variety of emotions and to the experience of suffering. When this is a regular occurrence in professional life, or when it reflects personal experience or is a particularly challenging trajectory of care, then the impact may be amplified. Nurses must look after themselves and their wider team to avoid short-term distress or longer-term burnout. This is much easier said than done, particularly given the growing demands on nurses and others to deliver care to growing numbers of people, often with increasingly complex needs.

Self-care takes many forms, ranging from reflection and debriefing, professional development, and time out of that particular context of care when necessary. Findings from a recent scoping exercise on self-care for nurses and midwives confirms that this is an area for development and further research (Sist et al, 2022). In the meantime, the literature reviewed in this exercise suggests that strategies focused on physical and psychological wellbeing, based on values and self-care, improve self-awareness and self-compassion, preventing or reducing negative outcomes (Sist et al, 2022). The same article highlights the value of mindfulness-based programmes in a supportive environment (Sist et al, 2022).

The organisation in which the nurse works plays an important part in creating a context in which the nurse is supported and can do the same for others. Part of care for oneself is to identify ways in which the organisation can better support nurses in their work of end-of-life care and to share such insights. The responsibility of the organisation and wider profession is to respond in a creative way to generate additional support (Sist et al, 2022).

> *"One of the greatest risks faced by nurses today is an unconscious slide from relationship-centred care to that which is transactional in nature"*

Conclusion

Nursing has always been central to end-of-life and palliative care delivery and will continue to play a vital role in the foreseeable future. While this is a responsibility, it is also a privilege and can be very rewarding, particularly when done well.

The principles described in this article provide guidance about how to transform care, which can often feel demanding or relatively inconsequential, to an experience that exhibits the very best of nursing practice. It is recognised that how we care for the dying is a litmus test of a good health system as well as a responsible society. Nurses, along with the organisations in which they work and their professional bodies, have an opportunity to refine such care and participate in effort that affords people – who are arguably at their most vulnerable – the most supportive and respectful of care. These principles, we would suggest, support such an opportunity. **NT**

- The next article in this series explains how to adopt a rehabilitative palliative care approach

References

Bao J et al (2019) Multimorbidity and care dependence in older adults: a longitudinal analysis of findings from the 10/66 study. *BMC Public Health;* 19: 585.
Beach MC et al (2006) Relationship-centered care: a constructive reframing. *Journal of General Internal Medicine;* 21: S1, S3-S8.
Cagle JG et al (2017) Caring for dying patients in the nursing home: voices from frontline nursing home staff. *Journal of Pain and Symptom Management;* 53: 2, 198-207.
Caper K (2017) *Hopsice Care in the UK 2017: From Numbers to Insight.* Hospice UK.
The Choice in End of Life Care Programme Board (2015) *What's Important to Me. A Review of Choice in End of Life Care.* Department of Health and Social Care.
Department of Health (2016) *Our Commitment to You for End of Life Care: The Government Response to the Review of Choice in End of Life Care.* DH.
Department of Health (2008) *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life.* DH.
Donne J (1959) *Devotions upon Emergent Occasions, together with Death's Duel.* University of Michigan Press.
Etkind SN et al (2017) How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine;* 15, 102.
Goodrich J et al (2015) *Resilience: A Framework Supporting Hospice Staff to Flourish in Stressful Times.* Hospice UK.
Haggerty JL et al (2013) Experienced continuity of care when patients see multiple clinicians: a qualitative metasummary. *Annals of Family Medicine;* 11: 3, 262-271.
Horton S (2021) The personhood of the palliative care nurse. *ehospice.com,* 25 October (accessed 13 May 2024).
Islam I et al (2021) Before the 2020 pandemic: an observational study exploring public knowledge, attitudes, plans, and preferences towards death and end of life care in Wales. *BMC Palliative Care;* 20: 116.
Johnston B et al (2015) The person behind the patient: a feasibility study using the Patient Dignity Question for patients with palliative care needs in hospital. *International Journal of Palliative Nursing;* 21 : 2, 71-77.
Knaul FM et al (2018) The Lancet Commission on Palliative Care and Pain Relief: findings, recommendations, and future directions. *The Lancet: Global Health;* 6; S5-S6.
National End of Life Care Programme (2011) *Route to Success: The Key Contribution of Nursing to End of Life Care.* NEOLCP.
NHS England (2019) *The NHS Long Term Plan.* NHSE.
Reimer-Kirkham S et al (2016) 'Close to' a palliative approach: nurses' and care aides' descriptions of caring for people with advancing chronic life-limiting conditions. *Journal of Clinical Nursing;* 25: 15-16, 2189-2199.
Rodríguez-Prat A et al (2016) Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography. *PLoS One;* 11: 3, e0151435.
Samarasekera U (2022) Ros Taylor: seeing palliative care as relational. *The Lancet;* 399: 10327, 783.
Saunders C (1959) Should a patient know...? *Nursing Times;* 16 October, 994-995.
Sist L et al (2022) Self-care for nurses and midwives: findings from a scoping review. *Healthcare;* 10: 12, 2473.
Skilbeck JK et al (2018) Making sense of frailty: an ethnographic study of the experience of older people living with complex health problems. *International Journal of Older People Nursing;* 13: 1, e12172.
St Christopher's (nd) The Lantern Model: a contemporary model of nursing. *stchristophers.org.uk* (accessed 13 May 2024).
Wee B et al (2021) Reviewing our ambitions for palliative and end of life care. *england.nhs.uk,* 17 May (accessed 13 May 2024).
World Health Organization (2020) Palliative Care. *who.int,* 5 August (accessed 13 May 2024).