Nurses can be ‘change agents’ in end-of-life care

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Nurses have the power to be “absolute change agents” in end-of-life care, according to hospice nursing leaders who are on a mission to help nurses in all sectors recognise and articulate the value they can bring to people during death and bereavement.

To mark the International Year of the Nurse and Midwife in 2020, senior nurses Professor Heather Richardson and Marie Cooper from St Christopher’s Hospice in London embarked on a project to celebrate nursing in palliative and end-of-life care.

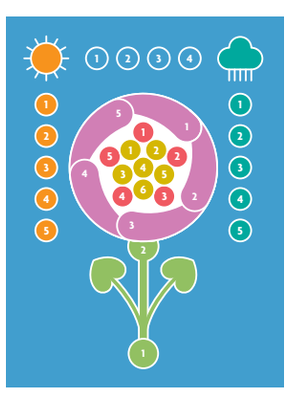
Through their work they said they were “shocked” to discover there had not been a contemporary model of nursing for people at the end of life published for almost 30 years, so they decided to develop one themselves. The result is the Lantern Model.

It is based on a person-centred nursing framework and features seven components that, when working in sync, “get the greatest impact from the nurse,” said Professor Richardson, one of two joint chief executives at St Christopher’s. It has been informed by published evidence, feedback from a wide variety of nurses about their own experiences, as well as comments from patients and families.

At the heart of the model, which is displayed in the shape of a flower, are the patient outcomes that nurses working in line with it can expect to achieve. These include comfort, dignity and respect, and participation in care. It describes the processes that nurses deliver to contribute to these outcomes, such as connecting, future planning and accompanying. Also set out are the “personal prerequisites” for a nurse who is working with people at the end of life: compassion, self-knowledge, confidence, generosity and courage.

The previous lack of an up-to-date model meant nurses sometimes struggled to articulate what they do, said Professor Richardson. For example, she noted how one hospice nurse she worked with had recently chosen to stop off on her way home from a night shift to put up a syringe driver for a patient at their home, because she knew the community nursing team had been delayed. “She would never have described that as a key part of her nursing practice, but she wasn’t doing it outside her registration,” said Professor Richardson. “She had connected with that person’s family on the telephone earlier, knew they were suffering, and she was going to see through that bit of care and was going to enable that man to die well.”

Overview of the Lantern Model



The model has seven key components described in the narrative below.

Outcomes

High-quality nursing seeks to make a difference to people’s health and lives. At the heart of our model are the outcomes nurses working to this model can expect to achieve on behalf of those for whom they provide care.

1 Knowledge
2 Comfort
3 Dignity and respect
4 Safety
5 Opportunity to participate
6 New skills and confidence.

Context of care

These outcomes reflect contemporary challenges and opportunities which nurses of today and tomorrow will want to grasp, and the macro context shaping their practice.

1 Society’s fear of death
2 Individuals’ desire for agency, independence and self-determination
3 The uncertainties of contemporary dying
4 A health system under pressure.

Processes of nursing care

Nurses will contribute to these outcomes through various processes of care that they deliver directly and in which they are central.

1 Connecting
2 Future planning
3 Coaching and caring
4 Accompanying
5 Saying goodbye.

Support by the wider multi-disciplinary team (MDT)

Some nursing processes are most effective when they are supported by input on the part of other professionals also involved in end of life care.

1 Recognising dying
2 Inviting important conversations about today and the future
3 Providing enhanced symptom management, psychosocial care and rehabilitation
4 Supporting continuity of care
5 Caring for colleagues.

Personal prerequisites

The nurse will only enact their processes of care and work effectively as part of the MDT if they have the right personal prerequisites.

1 Compassion
2 Self-knowledge
3 Confidence
4 Generosity
5 Courage.

Organisational conditions

The nurse’s impact will be enhanced if organisational conditions to support their effort are optimum.

1 Space to care
2 Access to a multi-professional team and other sources of help
3 Commitment to a happy cohesive workforce
4 Availability of personal and professional development opportunities
5 Risk-confident and supportive culture.

Key tenets that shape and guide the care provided

The best nursing at the end of life is rooted and supported by key tenets which serve to guide all their efforts.

1 A contemporary philosophy of palliative and end of life care
2 Finding ‘the person in the patient’.

Professor Richardson said if the nurse in her example were to see the model, she should know “her compassion and her sense of duty, in that respect, is something that is about the value of nursing”. “It’s not just about her being a good egg, it is part of being a good nurse,” she said.

The hope is the model will not only offer a shared language and clarity around the unique offer of nurses at the end of life, but will also make a case for increased investment in recruitment and retention. One of the components is focused on the support nurses need from their organisations to deliver the best end-of-life nursing care. This includes providing nurses with the right space to work in and access to a multidisciplinary team, having

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a supportive culture, and offering personal and professional development opportunities.

Ms Cooper said she knew of "very few" organisations that invested financially in their nursing workforce in terms of mentoring and coaching. "Things have been paired right back to mandatory training [and] it's gone online, which nurses must do in their own time often," she said. The Lantern Model recognises that employers "have a responsibility to invest in their staff", she noted.

Professor Richardson said they had met nurses who had left "really important roles" in hospitals, because they had not been given the facilities to provide the kind of care they had wanted to. She highlighted that organisations could make "small shifts" to the working environment, or the support they provided, that could "make a massive difference to your retention as well as to your outcomes for patients".

The model is intended for nurses across all settings and levels who deal with patients at the end of life and would be particularly pertinent for non-hospice settings, according to Professor Richardson. She said: "We do have an eye on our hospice colleagues, but our bigger concern is for the majority of people who die outside of hospice care. We are absolutely motivated by the inequities and the inequalities that we see across the board. Nurses could be absolute change agents in making care more equitable, more acceptable, and there being some parity of quality regardless of where you die." She highlighted that, at present, how a person died depended on factors, such as setting, age and diagnosis. "All of that could be different if nurses were empowered," she said.

Before work on the Lantern Model started, the focus of the project – which was supported by the Florence Nightingale Foundation and the Burdett Trust for Nursing – had been on looking at past and present nurse pioneers. By reviewing the lives of nurses such as Florence Nightingale and Dame Cicely Saunders, founder of the first modern hospice, they brought together a community of 30 nurses from 15 countries who shared similar attributes as these pioneers and were considered current-day "game changers" in palliative and end-of-life care.

It was when the first lockdown was announced that Professor Richardson and Ms Cooper decided to spend time working on a new model. In fact, the pandemic would go on to make the work even more timely, as it shone a light on the role of nurses in all settings in supporting people at the end of life. Professor Richardson noted: "We've seen even more inequity as a result of Covid."

The flower in the Lantern Model is rooted in two "key tenets that shape and guide the care provided" – one of which is around "finding the person in the patient". Ms Cooper said the importance of this tenet had been brought to the fore during the pandemic and nurses had shown their commitment to achieving it "in spite of all the isolation". "They have been so creative, along with their medical colleagues and others, in finding ways to connect with the family," she said.

Ms Cooper added: "You'll notice in our model, there is nothing technical in it. It's the principles that you apply within your world, whether in an intensive care unit or in a [homeless] hostel. Nurses can realise how well they are doing – 'I am connected with my patient, I am understanding their world, I have got the courage to go the extra mile'. It's a way of affirming nursing, not just saying what they're not doing, it's saying that actually this is research-based, look how well we're doing guys."

Work is now underway to get word out about the model and collect feedback. Professor Richardson stressed that the model should not be taken "lock, stock and barrel", but could be used however individuals or organisations saw fit. She noted how a couple of nurses had started using the model to recruit against the prerequisites, rather than just competencies. "I wonder whether we would get a different kind of cohort if we recruited for courage, for example, or for generosity, or for compassion, rather than a skill base around 'can you do this, can you do that and so on'," said Professor Richardson. "I think that's part of the shift that we would really like to see in recruitment."

Another opportunity was to use the model in education institutions to shape curricula and Professor Richardson hoped it would get picked up by national organisations. She believed, in the light of Covid-19, that there was a recognition that "end-of-life care needs to be better".

St Christopher's is planning to use the Lantern Model to form the "underpinning philosophy" for a programme it is launching called Palliative Works, which is around supporting and developing clinical nurse specialists in palliative care across the NHS and voluntary sector.

Professor Richardson said one of the most positive things that had emerged from the Year of the Nurse project was that it had started conversations on palliative and end-of-life care nursing and brought together nurses from around the world, which she wanted to continue. "The output I'm most excited about is not the Lantern Model, it's the new energy, the new conversations, the new connections, and the new awareness of people about the value of nurses as leaders," she added.