Using the Gold Standards Framework to deliver good end of life care

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None declared

Abstract
The aims of excellent end of life care (EOLC) and nursing care are at the heart of healthcare. Chelsea and Westminster Hospital NHS Foundation Trust, a multi-site London teaching care provider, recognises and values the importance of good EOLC, and the quality of EOLC is used as one of the key metrics in assessing the quality of patient and family care across the trust.

The principles of EOLC, including those enshrined in the Gold Standards Framework (GSF), are closely aligned with the trust's core values. Each member of staff is encouraged and supported, through the GSF process, to recognise and respond as befits their role in implementing the principles of EOLC, agreed by staff, and by patients and their relatives.

This article describes the experience of, and collaboration between, trust staff and members of the GSF team, who have worked together for the past 18 months, and how this work has placed EOLC at the heart of patient care and staff recruitment. This collaboration has helped to enrich the culture of compassion and care that the trust aims to deliver, and to focus on providing person-centred care.

Keywords
end of life care, Gold Standards Framework, nursing management, person-centred care

Background
German philosopher Martin Heidegger wrote that every human being is moving towards their own death. Rather than seeing this as negative, Heidegger suggested that, if we acknowledge this reality, it sets us free to live life as we truly want to. For many nurses and nurse leaders, Heidegger’s call to live life to the full is the inspiration for delivering patient-centred nursing care.

Chelsea and Westminster Hospital NHS Foundation Trust is a large London teaching care provider with multiple sites and cares for adults and children who require specialist and non-specialist care.

As part of its extensive range of other patient-centred services, the trust has one of the largest HIV and sexual health services in the UK, a large maternity unit and a children’s hospital. While most patients return home, some are moving towards the end of their lives and may die while in the hospital, or return home to do so.

The trust recognises the importance of good end of life care (EOLC), and uses the quality of EOLC to measure delivery of good patient care, in agreement with the governors and local clinical commissioning groups. The delivery of consistently good EOLC, 24 hours a day, seven days a week, can be achieved only if clinical and non-clinical staff recognise their roles in this task. The trust, led by nursing, has recognised that the principles of EOLC can help enrich its culture of compassion and care, and attract nursing staff who embrace the same values.

EOLC has been defined as care that helps all those with advanced, progressive, incurable illness to live as well as possible until the day they die (General Medical Council (GMC) 2010). Unfortunately, we have become a death-denying society, sheltered by lack of exposure to, avoidance of and the over-medicalisation and specialisation of caring for those who are dying.

In reality, caring for people moving towards the end of life is a human task built on sensitivity and humility, coupled with good symptom management, which are core values of nursing.

In 2014, the trust made the following commitments to all adults and children moving towards the end of their lives:
» When you are moving towards the end of life, we will support you and your family sensitively to ensure your needs and wishes are met, and enable you to die in your preferred place of care.
» When you are approaching the end of your life, we will offer you the opportunity to be involved in your care planning. This includes an assessment of your needs and preferences, and an agreed set of actions reflecting these choices.

» We will work to ensure that you and your family receive excellent care in accordance with your wishes, at all times of the day and night. We will work with our community partners to ensure this happens.

» We will monitor how we are doing by talking to you and your family, taking part in national surveys, and by immediately addressing any concerns.

» The trust will offer you personalised care based on your wishes and needs. This includes attending to your physical, social, emotional, spiritual and religious needs.

» We recognise the importance of your family, friends and support network, and that they have the right to have their own needs assessed and reviewed, and to have a carer’s plan.

» To care for you and your family, we will ensure that all staff and volunteers working in the trust are aware of the issues surrounding care at the end of life, particularly the importance of excellence in communicating.

» We will participate in research to improve patient and family care at the end of life. To support all staff to deliver these commitments, the trust, guided by the EOLC steering group, wanted to build on its EOLC strategy. It therefore approached the Gold Standards Framework (GSF) Centre in End of Life Care team, based in the West Midlands, for support in using the GSF to bring together, and build on, all aspects of the trust’s EOLC strategy.

National context of end of life care

About half a million people, roughly 1% of the population, die in the UK every year, and one person dies about every minute. Just over 100 years ago most people in the UK died from infection, accident and trauma, and childbirth, many had short trajectories of illness and most died in their fifties. This is still the case in many developing countries. Now most people in the UK die from frailty, dementia, comorbidities, heart disease, chronic obstructive pulmonary disease and cancer, and there is a consequent shift in lifespan, with an increasing number of people over 85.

In the developed world, with changing demographics, we face a different kind of challenge. More people are living longer with serious, incapacitating conditions, more are nearing the final year or so of their lives and in 2015, for the first time for many years, the death rate started to rise (Office for National Statistics 2015). This presents new challenges of meeting demand with inadequate resources, potential over-use of hospitals and over-medicalisation, and inadequate focus on early detection, prevention and support in the community to prevent expensive and avoidable hospitalisation (Macdonald and Loder 2015). The healthcare system is still unprepared for this change, and nowhere more so than in hospitals.

Despite most people expressing a preference to die at home where possible, just less than half still die in hospital, and about half of these could have died at home with more proactive and better supported community care (National Audit Office 2008). Despite the UK being rated top of the world end of life care league table (Economist Intelligence Unit 2015), and improvements since publication of the NHS end of life care programme and strategy (Department of Health 2008) and the Ambitions for Palliative and End of Life Care report (National Palliative and End of Life Care Partnership 2015), care is still often reactive and inadequate (Parliamentary and Health Service Ombudsman 2015).

Poor care of patients in the final days of life has been much cited in the media and national policy, about the withdrawal of the Liverpool Care Pathway (Neuberger 2013) and with a particular focus on inadequate care of dying patients in hospital.

EOLC, defined in national policy terms as care in the final year, rather than the final days, of life (GMC 2010), has received much attention in National Institute for Health and Care Excellence (NICE) guidance (NICE 2013), and from the Care Quality Commission (CQC), and it is now recognised that it is the business of all healthcare professionals and an important part of the work of every member of hospital teams. But is the health service prepared for this challenge, how well are hospital staff trained in this area, and what can be done to develop more proactive, joined-up, person-centred care for people in the last chapter of their lives, to enable them to live and die well in the place and manner of their choice?

End of life care in hospital

Most people have two to three hospital admissions in the final year of life, about 30% of hospital patients at any one time are in their last year of life (Clarke 2014), and an estimated 10% of patients die after admission.
The UK has excellent specialist palliative care services but they have traditionally concentrated on patients with cancer. It is now time to also focus on patients who are facing the end of their lives with non-malignant conditions such as dementia, heart failure, kidney failure or neurological disorders. The recent ministerial response to the review of choice in end of life care (Department of Health 2016) affirms the government’s commitment to improving personalised EOLC.

The broader understanding of the scope of EOLC, and the recognition that about one third of the NHS budget is spent on patients in their last stage of life (Georghiou 2012), have highlighted the relevance of every area to all healthcare staff, especially in hospitals. The inclusion of EOLC as one of the eight core domains in CQC hospital inspections since 2014 has revealed inadequacies in hospital care, with almost half of hospitals being rated poor or inadequate in EOLC (CQC 2015). Many hospital boards are now taking notice and are instituting changes.

Accepting that around 30% of all hospital beds are occupied by patients potentially in the last year of their lives, rather than perceiving death as a sign of failure, helps in the drive to improve care in every corner of health and social care services. The provision of good quality EOLC is core business for every hospital.

Gold Standards Framework

Development

The Gold Standards Framework (GSF) Centre in End of Life Care is the national training and coordinating centre for all GSF programmes. Since its launch in 2000, it has helped generalist front line health and social care professionals improve care for everyone in the final year of life. Many thousands of doctors, nurses and carers have received training from the GSF team that has helped them improve the care of millions of people, so that they are more likely to live well and to die well in the place and manner they choose.

The essence of GSF training is to enable generalist staff to facilitate their roles in improving care for patients in the final year or so of life. This is achieved through a simple three-step process, namely identify, assess, plan (Box 1), which enables more proactive care in line with patients’ preferences.

Earlier identification of patients is the first and sometimes most challenging step. However, this is supported by using the GSF Proactive Identification Guidance, a set of clinical parameters that help indicate when a person may be moving towards the end of life (GSF Centre in End of Life Care 2011) and which support Clarke’s (2014) estimate that 30% of all non-elective hospital patients at any one time are in their last year of life.

The guidance encourages discussion in the multidisciplinary team and, using a needs-based coding system, ensures the right care for the right patient. Patients are offered an initial advanced care planning discussion, and care is planned by the team in a way that meets patients’ needs effectively in living and dying well.

Achievements

An accreditation process involves before-and-after evaluations, online after-death analysis reports, portfolio submission, and assessment visits after GSF training. GSF-accredited care homes and GP practices have halved the number of inappropriate hospital admissions and doubled the number of people who can live and die in their preferred place (GSF Centre in End of Life Care 2015). They also achieve high rates of early identification of patients in their final year of life, offer most patients advanced care planning discussions to clarify needs, wishes and preferences, and provide better care in the final days of life and better support for carers (GSF Centre in End of Life Care 2015).

BOX 1. Proactive care with the Gold Standards Framework: identify, assess, plan

- Identify the right patients, particularly people with non-cancer and from care homes.
- Assess clinical and personal needs.
- Plan living well and dying well with proactive integrated cross-boundary and coordinated care, and dying where they choose.
The accreditation process and quality hallmark award scheme for hospitals have been endorsed by the British Geriatrics Society and was recently approved by the CQC as the only ‘information source’ and approved accreditation process in EOLC for hospitals. Findings from the first eight accredited hospitals show earlier identification of patients, better advanced care planning discussions and fewer days in hospital, as well as qualitative improvements in staff confidence, coordination and communication with GPs and other community services (GSF Centre in End of Life Care 2015) (Box 2).

Implementation
The trust began the process of implementing the GSF standards in June 2015, initially focusing on six clinical areas including medical, surgical and specialist wards, including adult and neonatal intensive care units. Each of these areas in the first phase had been nominated by nursing and medical staff who wanted to champion EOLC on their units. It was the first time the GSF principles had been applied to an adult or neonatal intensive care unit, and, although it was a challenge for the GSF team and the trust, it was regarded as important recognition of EOLC in all areas of the trust and a creative way of applying GSF principles.

Phase two began in March 2016, with another seven clinical areas, including the cardiology, stroke and respiratory wards, the acute assessment unit and two children’s wards, beginning work towards GSF accreditation. Phase three, which begins in March 2017, will involve the remaining wards. Each ward has a nurse and medical consultant GSF champion, supported by the ward manager, who is the EOLC lead for their clinical area, and guided by the trust-appointed GSF facilitator, who works two days a week. Monthly meetings, led by the assistant director of nursing and trust lead for EOLC, bring together the EOLC and GSF champions. The champions have the opportunity to share practice, including achievements and challenges. The challenges are often to do with supporting staff to take a proactive approach to EOLC recognition and planning alongside delivering daily care.

A baseline measurement is used on each ward, including a staff (clinical and non-clinical) survey on EOLC and a review of patient care. Members of the GSF team carry out ward visits to monitor progress and support staff, and further support is given through GSF workshops, led by the GSF team, every three months.

The GSF workshops, hosted at the trust, are an opportunity to meet and share experiences with medical, nursing and allied health professional colleagues from other hospitals who are also going through the accreditation process.

In the past year, the trust has officially launched the GSF programme with the support of patients and bereaved relatives, held Schwartz Rounds (staff-support reflection sessions) focusing on EOLC, medical grand rounds based on the GSF approach, and held a workshop on advanced care planning led by the GSF team and experts in the field. The grand rounds have been especially well attended by nurses, consultants, junior doctors and allied health professionals.

Challenges and opportunities
Great progress has been made in delivering the EOLC guiding principles across the trust, and in delivering the commitment to patients, progress that has been recognised by external visits by the GSF team, reviews, and patient and carer feedback. However, some findings and feedback show there is more the trust can do to improve the consistency of EOLC delivery.

Some of the ongoing work is focused on supporting staff, and during induction all

**BOX 2. Achievement of Gold Standards Framework-accredited hospital wards**

The Gold Standards Framework helps to improve:

- Quality of care.
- Coordination of care, with better communication with GPs, care homes and hospitals.
- Outcomes based on enabling more people to live well and die well, and reducing inappropriate hospitalisation.
- Earlier identification of patients declining, or in the final year of life, leading to more proactive care for those with life-limiting conditions.
- Earlier assessment and better listening to patients’ wishes through advanced care planning discussions, and providing care to meet their needs.
- Appropriateness of admission, halving hospital admissions and hospital deaths, so that more people die where they choose and fewer die in hospital.
- Staff confidence, job satisfaction, morale and retention.
Clinical and non-clinical staff attend a short session on the principles of EOLC that highlights each person's role.

All clinical staff also receive mandatory updates, and a rolling EOLC programme of teaching is delivered by trust staff and local partners. This includes a Health Education England locally funded programme, I Can Make a Difference, aimed at healthcare assistants, accredited modules, and simulated learning on EOLC for nurses, doctors and allied health professionals.

A new, locally designed care planning document, the Compassionate Care Agreement, is used to personalise care for those in the last days of life, and the trust is working with local GPs and community partners to coordinate patient-centred advanced care planning though a shared database called Coordinate My Care. The trust, recognising the central role of EOLC, has also invested in expansion of the specialist palliative care team to enable seven-day face-to-face patient support. This has resulted in a significant rise in earlier referrals, and better opportunities to plan and address patients’ wishes.

Although things have improved, challenges remain, and some nurses and medical staff are reluctant to talk to patients and their families about what they would like as they approach the end of their lives.

To build on the EOLC work, and recognising the benefits of the framework, the trust has committed to becoming a GSF-accredited hospital by 2018. Staff are encouraged and supported to take the lead on EOLC planning and discussions, rather than rely on specialists leading the way.

Thoughts and views

The GSF as a structure enables the trust:
1. To consider that a patient may be in the last year of life.
2. To bring that thought to the multidisciplinary team for consideration.
3. To support staff to raise the subject sensitively with patients and/or their carers, often in a process led by experienced nurses.
4. To engage and involve patients and carers in care planning.
5. To record plans carefully and share them with patients’ GPs and community teams for ongoing review and implementation.

Consultants from areas such as the HIV and stroke units have warned of the danger of doctors and nurses losing skills in leading EOLC conversations, and how the GSF has helped them and their teams to refocus.

Nursing managers from intensive therapy and the dementia ward have shared their progress in implementing the GSF, and explained how the principles are core to good care and closely aligned to the nursing profession.

The identification of patients who may be in the last year of life is central to the weekly ward multidisciplinary team meetings led by senior nurses and consultants. Staff report that they are becoming increasingly engaged in EOLC and feel better supported to identify and broach the subject, and that EOLC/GSF is a part of every nursing handover.

While some staff still regard EOLC as the domain of chaplains or specialist palliative care colleagues, there has been a shift in approach, and nurses and consultants increasingly lead this central aspect of patient care. Some comments from staff are set out in Box 3.

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**BOX 3. Staff comments on Gold Standards Framework (GSF)**

- “The GSF has provided a structure which has enabled the critical care team to re-examine their approach towards end of life care. Weekly multidisciplinary team meetings are held to discuss where patients are in their illness, and whether they are in the last 12 months of their lives, thus permitting more open discussions with patients and their families, underpinned by shared decision making for the patient” (Ward sister, intensive therapy unit).
- “This new approach is already making a great difference in improving care of those whose end of life is approaching. A more open conversation regarding the issues of death and planning for time remaining is important in identifying what the patient wants and needs at this stressful time for the patient, family and staff” (Consultant in HIV medicine).
- “The GSF greatly assists in highlighting those patients who are in the last 12 months of life. This encourages patients, family and healthcare professionals to come together to ensure care is truly person-centred” (Sister, stroke ward).
- “The GSF has provided the trust with a great opportunity to train staff, standardise patient pathways for end of life care, and ultimately improve the experiences of our patients, their families and friends. We have received excellent feedback from staff and families following the introduction of GSF within the trust. Our teams take a great pride in the care they provide and this programme provides them the opportunity to further develop our core standards. We are delighted to have been part of this work” (Director of nursing).
- “The GSF builds on existing principles and philosophy of palliative and end of life care within the neonatal specialty. It enables and empowers staff to ensure infants and their families consistently receive the highest quality care in accordance with national guidance” (Neonatal specialist palliative care nurse).
Learning opportunities
The GSF programme is a collaborative project involving ward-based staff, patients, carers, bereaved family members and the GSF team. While the trust’s EOLC programme has been greatly enriched by working alongside the GSF team, the team has in turn learned lessons from rolling out and adapting the programme to specialist, paediatric and neonatal care. This will hopefully be a great support to other hospitals embarking on GSF accreditation. Trust staff have joined the GSF team in parliament to talk to ministers and other MPs about their experience of using the GSF to support EOLC in hospital settings.

Like other NHS organisations, the trust focuses on delivering safe, efficient and high-quality care on a day-to-day basis. But this cannot be its sole focus, and it needs to look creatively at delivering care and supporting staff efficiently, and at how staff work in the future, including seven-day working, which requires strategic planning and investment.

Next steps
The scope of EOLC continues to grow thanks largely to the nursing leaders who champion the cause and work with medical and surgical colleagues, as well as with allied health professionals.

The rollout of the GSF programme is monitored and supported by the EOLC steering group, and progress is reported to the trust’s patient experience committee, the executive board and the local care-quality group. With the trust having embarked on phase two of the programme, the coming months will see the principles of GSF rolled out to all areas including the two emergency departments. Wards in phase one will soon be applying for accreditation.

Conclusion
Although it appears that the NHS is trying to deliver more care with less resources, this does not negate its central focus of delivering holistic, patient-centred care. We cannot talk about patient-centred care without being willing to engage with all aspects of people’s lives, including their physical, emotional, social, existential and spiritual needs. Nursing leadership, the focus on EOLC, and the work of the GSF can help us deliver and improve person-centred care.

References


