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End of Life Education in the Acute Setting: Opinion Piece

NB 2000 words – excluding references, tables and figures - 10 references only

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Abstract:

End of life (EOL) care should be seen as everyone's business in acute hospital settings; a focus on targeted education and training in EOL care has the potential to improve the delivery and experience of patients and their families. We discuss the challenges associated with providing end of life care education in acute settings, and make recommendations around what should be delivered, to whom, when and how, including the measurement of impact of educational interventions. To deliver excellent education, content and delivery need needs to be multifaceted, tailored to the needs of staff, and importantly led by the voices of patients and their families. We call on senior Trust executives to resource and support the development and delivery of an EOL care education strategy to improve competencies of all staff, fostering an organisational culture of person-centred end of life care throughout any acute setting.

Keys words: Terminal care, Education, Hospitals

***"I never asked, "is he dying?" ……maybe I should have…..?"* - Relative of a patient who died in hospital**

Introduction

Nearly half of all deaths in England occur in hospital, and by 2040 there will be over 100,000 additional deaths annually[1 2]. It should therefore be core business for hospitals to deliver high quality, person-centred care to patients in the last days of their lives, and to their families. Despite this, numerous government and charity reports over the past five years have highlighted instances of inadequate care experienced by patients towards the end of their lives, and by their family members who also need support at this challenging time[3-5]. Of all places of death, quality of care in hospitals is most likely to be rated by bereaved relatives as poor, and least likely to be rated outstanding or excellent[6].

For some of these deaths, a key component of care will be the input of specialist palliative care services. However, most end of life (EOL) care is, and will increasingly be, the responsibility of staff without specialist palliative care qualifications[7]. Moreover, the context of an aging population means this care will present increasing levels of complexity due to increased frailty and multi-morbidity. Education and training in care of the dying is urgently needed to ensure that *all staff* are "prepared to care", and to achieve the Ambitions for End of Life Care set by the National Palliative and End of Life Care Partnership[5]. We discuss the multiple challenges to achieving these ambitions, and make recommendations for providing appropriate education in EOL care in terms of content, timing and delivery, as well as methods to test effectiveness. In this article we consider EOL care within the definition in National Institute for Health and Care Excellence (NICE) quality standard, which looks at care for people who are likely to die within 12 months.

Who to educate and when?

Educating the right people in EOL care, in the right way, about the right things, is a challenge. The aspiration that high quality EOL care should be everyone's business means that the target audience for learning in acute Trusts is everyone, from the frontline clinicians to the ward receptionist, the housekeepers, porters and the patients and their carers. This means that a number of teaching and educational strategies are needed to suit these varying roles with different requirements of knowledge and practical competency - a huge task. Even if learners are limited to clinical staff, high turnover across professional groups requires frequent repetition of any training programme, making it labour and time intensive. It is therefore crucial that EOL care education is kept high on all agendas - strategic and financial - in order to maintain continuing professional development and maintenance of competency for all staff at all levels.

Senior support for the prioritisation of EOL education is especially important, as hospital staff have many demands placed on their training time and resources. EOL care education may seem less urgent a priority than learning about many other clinical topics such as sepsis or infection control. In the acute sector, as in other settings, it may be difficult to release staff from clinical duties for education. Consultants and registrars can be particularly difficult to engage in training outside their field of speciality. Leaders within acute Trusts can provide support by prioritising to EOL care education, and setting and monitoring expectations across all staff groups as part of the annual appraisal process.

EOL education should start at undergraduate level for all clinical hospital staff groups and continue on a regular basis throughout their careers[8]. Some hospital Trusts provide mandatory EOL care training at induction and annual updates, which captures a large number of staff. This can be useful for 'bite size' learning, but may be less effective for learning outcomes that require attitudinal and behavioural change[9].

Sustaining the effectiveness of EOL education is difficult. Many EOL change programmes, with education at their core, have had short-lived success, only to fail as skills fade over time or staff move on and the learning is lost. Although there is no definitive evidence to guide the frequency of updates, EOL education can be linked to revalidation cycles[8]. For clinical staff, education in EOL care should be reviewed regularly against competencies[9] to assess the need for further learning beyond that provided during induction or annual updates.

What should be included in EOL education?

EOL education needs to address the whole pathway from recognition that someone may be in their last year of life, through deterioration, to the dying phase and into bereavement for those left behind. There are several national EOL education frameworks available as resources across the UK. Examples include Health Education England's EOL competency framework[5 7 9] and asset based learning guidance[10]; the EOL care e-learning modules[11] and the EOL education framework from NHS Scotland[12]. Competencies vary from knowledge-based topics such as pain control, to teaching a member of staff to sit quietly with someone in suffering (Figure 1). EOL education competencies such as practical support, symptom management and care after death represent knowledge that can be acquired; others develop skills such as communication, whilst attitudinal changes such as dealing with uncertainty and allowing patients to make unwise or risky choices can also form part of an educational programme. A number of these subjects are challenging to teach and reflect the complex nature of caring for people at the end of life.

Most hospital Trusts in the UK have an in-house EOL education programme [8],however, it is not clear whether these programmes cover the breadth of competencies recommended in current national documents; if the programme includes all staff; and whether any consideration of local training needs has been included.

Fundamental to all EOL care competencies is person-centred practice that "recognises the circumstances, concerns, goals, beliefs and cultures of the person, their family and friends, and acknowledges the significance of spiritual, emotional and religious support" [11]. This sounds self-evident in theory but perhaps does not always translate into practice. Whilst some elements of more structured education can contribute to engendering this approach, it is important to see this as about more than just knowledge, skills, and attitudes – it's a about a *culture* of person-centred practice. When considering what to include in EOL care education and training, we advocate the importance of not only developing the competencies of staff, but also thinking creatively about how to develop and foster a person-centred culture around EOL care in the acute setting.

In the same way as healthcare needs to treat patients and their families as individuals, and tailor care to meet their needs, it is important to remember that staff also have unique and individual strengths and weaknesses. As such, we would suggest that a thorough assessment of staff training needs to be made prior to instigating new educational interventions. Staff confidence measured by self-assessment does not always correlate with competence, in fact, those with less skills often may over-estimate their ability[13]. We would suggest linking "local" information - such as the results of audit or quality improvement work, patient and carer experience, and themes from complaints and mortality reviews - to the education provided in order target areas most in need of improvement.

How can EOL care be taught?

Planning and delivering EOL education requires an approach that attends to the needs of the individual, the context of the learning environment as well as the learning objectives of each session. Education needs to be relevant and useful for learners, well delivered and accessible, and able to influence longer term care by developing and sustaining practitioners' knowledge, skills, attitudes, behaviours and values. The National Palliative and End of Life Care Partnership[5] Ambitions remind us of the importance of "knowledge-based judgement" in the delivery of EOL care. While this can be obtained to some extent through e-learning and/or classroom teaching, much of what we want to engender requires behavioural or cultural change, which is unlikely to be achieved through online or didactic teaching alone.

As examples, education around recognising the transition from active to palliative care, improving communication skills and providing emotional support to patients and families will need other approaches such as role modelling, interactive roleplay or simulation, and practice-based learning. Moreover, creative teaching approaches such as plays, blogs, literature and narrative approaches, can also remind learners that patients and families live in social contexts, not just in the biomedical contexts that staff in acute settings encounter them in. A multi-modal approach to EOL care education is optimal where possible delivered in multi-professional groups, which allow participants to 'modify negative attitudes and perceptions' and 'remedy failures in trust and communication' between professions and disciplines[14]. Finally, including patient, public and carer involvement in the design, delivery and evaluation of education can ensure the reality of our knowledge and actions is rooted in every day experiences. An example is the quote at the start of this article which expresses powerfully the impact of not communicating to their relatives that someone is dying.

How do we know if EOL education is effective?

The effectiveness of educational initiatives can be measured at multiple levels, each with their own benefits and challenges. Kirkpatrick's model of training evaluations[15] is helpful; where effects are considered in four progressing levels: reaction (e.g. satisfaction), learning (e.g. confidence, knowledge, attitudes), behaviour (e.g. in simulated or real interactions), and results (e.g. patient/family experiences or outcomes).

Most evaluations focus on reaction and learning of participants as these are simple to capture using self-reported questionnaires[16]. However, these are subject to reporting biases and cannot measure the true intended outcome of EOL care education - improved patient care. Assessing staff behaviours is a better way of demonstrating changes in clinical practice, yet can be challenging to achieve as using measures of staff behaviour can themselves be problematic. Although behavioural assessment tools can be useful for 'ticking off' objective clinical tasks, they may not be so reliable at capturing person-centred care. In some studies, participants were found to score 'higher' on behavioural measures of communication skills in simulated interactions than real interactions; does this mean staff are performing 'worse' in the real consultation, or are they individualising their communication in ways that these measures cannot capture?[17] As such, obtaining patient-level feedback (particularly when this can include maximising use of existing patient-level data) must be prioritised as the gold standard measure for person-centred end of life care.

Crucial to measuring the effects of staff education initiatives for impact on patients and/or families is thinking carefully and realistically about the intended effects an initiative may have, and then

choosing how to measure effectiveness accordingly. This needs to include a clear route from impact (of learning) on staff to impact on service users. Capturing basic elements of learner satisfaction, and testing confidence and objective knowledge before and after are good starting points. However, venturing beyond these standard learning outcomes to the patient and family level requires a more innovative approach, which can include measuring experience (e.g. quality of care) and/or outcomes (e.g. symptoms). Most importantly, measures must match the aims of the training. For example, effectiveness of training in pain management at the EOL could be measured through comparing a trained and untrained group of staff on their knowledge of pain management techniques, and comparing their patient's reports of pain). For interventions aimed more at cultural change than discrete events this link can be particularly difficult to pinpoint, and may require inclusion of qualitative evaluation components. We recommend the funding of educational initiatives, prioritising programmes that have been shown to demonstrate change at the behaviour and/or patient care level. Current un-evaluated initiatives and novel proposals should be supported to link with academic partners to help undertake a high-quality evaluation. Fundamentally, unless an educational programme achieves improved EOL care for patients and their relatives, the organisation providing the training should question the purpose of delivering it.

Conclusion

Delivery of EOL care education in the acute sector is not easy, but it is important. The support of senior Trust executives can be key to ensuring that acute care organisations resource and promote the development and delivery of a specific EOL care education strategy. These programmes should identify the staff members who may benefit from targeted EOL care education and look at what point competencies should be achieved, and then updated. Use of national guidance and competencies blended with local themes from audit and quality improvement, complaints and mortality reviews and importantly patient and carer experience, can help tailor content. An ideal programme should make use of up to date educational tools and methods that have been demonstrated to impact patient care and critically evaluate the impact of the delivered intervention. Advancing the field of EOL care education can be achieved by acute Trusts engaging in research with their academic partners in order to review and refine programmes across developing care networks.

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Figure 1 End of Life Care Core Skills Education and Training Framework from Health Education England, Skills for Health, Skills for Care. End of Life Care Core Skills Education and Training Framework[9]

	Competency Area
1	Person-centred end of life care
2	Communication in end of life care
3	Equality, diversity and inclusion in end of life care
4	Community skills development in end of life care
5	Practical and emotional support for the individual approaching the end of life
6	Assessment and care planning in end of life care
7	Symptom management in end of life care
8	Working in partnership with health and care professionals and others
9	Support for carers
10	Maintain own health and wellbeing when caring for someone at the end of life.
11	Care after death
12	Law, ethics and safeguarding
13	Leading end of life care services and organisations
14	Improving quality in end of life care through policy, evidence and reflective practice