

End of Life Education in the Pre-Registration Nursing Curriculum: Patient, Carer, Nurse and Student Perspectives

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Abstract

Providing good quality care for dying patients has been highlighted as a national priority in the UK. The End-of-Life (EOL) care strategy outlines how patients should be cared for to ensure that they experience a 'good death' (DH 2008). Nurses have an important role to play in the delivery of EOL care and need to be knowledgeable about the palliation of symptoms and the social context of death and dying (Williams and Field 2002). Traditionally, the pre-registration nursing curriculum has had a limited emphasis on EOL care (Field & Kitson 1986, Dickinson 2008). While there have been significant developments in nurse education in the last decade, the amount of EOL content in nurse education remains inadequate (Allchin 2006, Brajtmann et al, 2008). Drawing on literature mainly from the UK and USA, this review explores from the perspectives of students, newly qualified nurses, patients and carers the outcomes of EOL education. It reviews the evidence to determine whether newly qualified nurses are adequately prepared to deliver quality care to patients at the end of their lives. The evidence suggests that despite a greater emphasis on EOL care in nurse training (Dickinson et al 2008), adequately preparing nurses remains a challenge to educators.

Key Words: End-of-life care / Nurse Education/ Nurse Perspectives/ Patient and Carers' views

Introduction

Providing high quality care for dying patients and their families has been highlighted as a national priority in the UK. Policy documents (DH 2000, 2003, 2008) and the national service frameworks for heart disease, cancer and older people have identified EOL care as an integral part of patient care. The strategy for End-of-Life (EOL) care launched recently by the Department of Health outlines how patients should be cared for to ensure that they experience a 'good death' (DH 2008). It reminds us that how dying patients are cared for is an indicator of how we care for all sick and vulnerable people. The strategy also points out that good EOL care does not stop at the point of death and that all nursing staff should be responsive to carer and family wishes and cultural and spiritual needs in the bereavement phase.

The strategy recommends that EOL care be embedded in nurse training at all stages; in induction programmes and continuing professional development. It recognises that while specialist nurses require the highest level of competencies, the group with the greatest training needs are those who come into contact with dying patients regularly, although it may not be part of their core work in non-specialist healthcare settings. Implicit in this statement is the requirement for pre-registration nurse education to address perceived shortcomings in EOL care.

While the death of a patient is an event that all nurses will face, historically, the pre-registration curriculum has failed to directly address this issue (Quint 1967, Kiger 1994). Quint's (1967) landmark study on nurse education highlighted considerable

inadequacies and subsequently influenced the way in which death and dying was taught in nursing schools. Not until the birth of the hospice movement did death education adopt a more holistic approach. Nonetheless, despite an increasing awareness and inclusion of death education in pre-registration curricula (see Dickinson et al, 2008), there is evidence to suggest persistent shortcomings in the nursing profession's ability to meet the needs of dying patients. Allchin (2006) thus comments that nurse educators for more than thirty years have been calling for a greater emphasis in nurse training on EOL care, with this lack of education reflected in the quality of EOL care provided to patients (Brajtman et al 2009).

The provision of quality care for dying patients remains a major challenge (RCN 2002, Costello 2006). It has long been recognised that the majority of people die in acute hospital wards rather than home or hospices. This has led to a number of initiatives designed to transfer best practice for dying patients from hospices to hospitals. Despite these efforts, nurses are working in hospitals and community settings without knowledge of how best to assist patients and families facing the end of life (Malloy et al 2006, Burt et al 2008). Hence, partners and family carers may be excluded from EOL decisions and patients may not be enabled to return home to die if that is their wish. In addition, staff are not taught to recognise that death does not always represent a failure of the healthcare system or indeed, are provided with ongoing training in this area (DH 2008).

It is important to note that ascertaining the quality of EOL care services is problematic not least because of the multiplicity of influencing factors (Aspinall et al 2003). Nonetheless, policy directives demand that effectiveness and quality are assessed in order to inform service development and clinical care. One indicator used to assess service quality is patient and carers' views and experiences. Also, as end users of health services and recipients of care, patients and their relatives are increasingly involved in the delivery of education for nurses (Repper and Breeze 2007). Thus patient and nurse perspectives are particularly pertinent when exploring the adequacy of education on EOL care.

Whilst ongoing education is seen as pivotal to the provision of high quality EOL care (DH 2008), other factors may influence patients' and carers' views. The setting in which care is given, cultural values, organisational constraints and individual circumstances are all factors that impact on the delivery of care and influence perceptions. Furthermore, education is a complex concept that in the professional context focuses on application and outcomes to ensure that individuals are equipped with the knowledge and skills necessary for clinical practice. Cognitive, affective and psycho-motor elements shape EOL education as is the case with all adult learning (Woolhouse et al 2001).

The discussion below explores the effectiveness of end-of-life education within nurse training. It reviews the evidence to determine whether newly qualified nurses are adequately prepared to support dying patients at the end of their lives. It consists of three main sections which include the perspectives of patients and carers, students and registered nurses.

Methodology

The literature on educational programmes and nurses', patients' and carers' experiences can be multidisciplinary; consequently, a separate search strategy was formulated for each of the major bibliographic databases in health, education and social science. Seven databases; ONCL First Search, ASSIA, PsychInfo, CINAHL,

MEDLINE, EMBASE, BNI and AMED were searched using the keywords; patient's and carers' views, nursing students, end-of-life care, palliative care, nurse education, and pre-registration curricula. The search was extended by searching the reference lists of located papers for pertinent articles and by hand searches of what were thought to be the most relevant nursing and palliative care journals.

Inclusion criteria were papers relating to patients' and carers' views on end-of-life care experiences, student and nurses' experiences of death and dying patients, and outcomes of nurse education programmes about EOL care. The search was limited to papers written in the English language and published between 1995 and 2009. Certain seminal papers pre-1990, which provided evidence of the development of EOL education in pre-registration programmes, were included.

The results were filtered to remove duplicates, non-peer reviewed papers, items about patient education, educator experience, and learning styles. From a possible 96 articles identified, 44 met the inclusion criteria and were included in the review. Of these 25 papers originated in the UK, 13 from the USA with the remainder coming from Canada (n=1), Australia (n=1) and Scandinavia (n=1). A number of themes were identified and are discussed below.

Patient and carer perspectives

The overall purpose of EOL care is a 'good death' for individuals whose condition cannot be cured (Mercer and Feeney 2009). The origins of a 'good death' ideology lie within the hospice philosophy that has become embedded in contemporary Western palliative care and EOL education (Bradbury 2000, Costello 2006). Emphasis on a holistic approach, that values the whole person in individual context, is central to palliative care principles that influence understandings of 'good death'. Although symptom management has come to be seen as an important component of a 'good death', the evidence suggests that communication skills are an important factor in judging the quality of care received (Woods et al 2000, Johnston and Smith 2006) with modules on communication skills featuring heavily within EOL nurse education (Dickinson et al 2008).

In Johnston and Smith's (2006) phenomenological study that utilised in-depth interviews with 22 dying patients and 22 registered nurses, differences were reported in patients' and nurses' views about effective communication. Nurses identified effective communication as a determinant of quality care, particularly verbal components such as the provision of information and facilitating dialogue. Patients, however, highlighted, instead, the importance of listening and interpersonal skills on the part of nurses. Other priorities for patients were qualities such as kindness, warmth, compassion and genuineness, being treated as individuals and being supported to maintain independence and control over their lives. Patients expected nurses to meet their needs by being there for them, providing emotional support, comfort and spending time with them, with these non-verbal components of communication highly valued (Johnston and Smith 2006).

These findings align with those of Woods et al (2000) whose small-scale study involved 15 terminally ill patients, 10 of their carers and 19 bereaved carers. Patients and carers in Woods et al's (2000) study judged the quality of care on the basis of personal touches such as generosity with 'private' time and simple acts of kindness shown by nurses. Patients' reported that 'knowing someone was there' was the most important contribution made by nurses. These gestures, demonstrating nurses' care and support, were valued highly by patients.

Communication also featured in the systematic review of 123 studies on the information needs of patients and caregivers in the later stages of life-limiting illness conducted by Parker et al (2007). Patients and caregivers expressed a preference for health professionals who showed empathy and honesty and who encouraged questions. Information of a practical kind was universally welcomed by patients while a lack of it caused carers to doubt their ability to provide effective care (Woods et al 2000).

In contrast, Clayton et al (2005), reporting on qualitative research that used both focus groups and interviews with 19 palliative care patients, 24 carers and 22 palliative care professionals in Australia, found that patients did not want detailed information about future symptoms; they wanted to know that they would be pain free and supported through whatever problems might arise. In post-bereavement studies, dissatisfaction with the adequacy of care provided stemmed from a sense of patients being 'devalued', 'dehumanized' or 'disempowered' by nursing staff (Rogers et al 2000). Patients' criticisms also included inadequate symptom control (Skilbeck et al 1997) uncaring attitudes (Woods et al 2000) and a lack of information and emotional support (Fincham et al 2005, Skilbeck and Payne 2005, Johnston and Smith 2006). These criticisms involve cognitive, psychomotor and affective domains of learning that EOL education in pre-registration curricula is designed to address (Brien et al 2008).

Nurse and student perspectives: death as a negative experience

Nurses often have vivid recollections of their first experiences of death (Blum 2006, Cavaye 2009). It has been identified as the clinical experience that has the most profound emotional impact on nurses (Kiger 1994, Beck 1997) and is mentioned by students as a common fear when entering training (Loftus 1998). For example, in Kiger's (1994) qualitative study students (n=24) reported that death was a predominant feature in their images of nursing. At the start of their training students had anticipated difficulties with the emotional care of dying patients, the pain of seeing them suffer, shock of seeing a dead body and the difficulty of dealing with bereaved relatives. Students' accounts were underpinned by inexperience with death and a concern that this might lead to an inability to cope or 'do the right thing'. When anticipating possible encounters with dying patients, students expressed feelings of dread, sadness, frustration, helplessness and anxiety. Likewise, following the death of patients, Loftus (1998) found that nurses experienced feelings of sadness, anger and guilt.

More recently, Allchin's (2006) study explored the impact of death on 12 student nurses providing care for dying patients during their rotation in adult nursing. Drawing on data from in-depth qualitative interviews, she found that students experienced initial hesitancy and discomfort, which was complicated by a lack of certainty about their own roles in dealing with dying patients. They expressed feelings of awkwardness at being involved with others at 'a very personal time' but these lessened over time as nurses got to know their patients better and their interpersonal skills improved.

Although students in these studies felt that experiences of death supported their clinical and professional development (Loftus 1998, Allchin 2006), their responses indicate gaps in knowledge, skills acquisition and further educational needs. Hence, calls for nurse training programmes to place greater emphasis on EOL care (Allchin 2006; Brajtmam 2009).

Further evidence of this need is provided by studies that suggest that anxiety about dealing with death and bereaved relatives is not confined to student nurses (Hopkinson et al 2003, Tyree et al 2005, Weigal et al 2007). Costello (2006), for example, used in-depth interviews to explore registered nurses' experiences of death and dying in hospital wards. Costello's (2006) small study of 29 registered nurses suggests that management of death in hospitals is a source of conflict for nurses and their different experiences of death were based on the extent to which nurses were able to exert control over the dying process. 'Good deaths' focused less on patients' needs and the dying process and more on nurses' ability to manage organisational demands. These findings are in accord with others which suggest that the fewer difficulties patients experience in their journey towards death, the greater the likelihood of the death being perceived positively by nurses (McNamara 2001, Hopkinson et al 2003).

Nurses cope with their fears and anxieties about interacting with dying patients by masking them and by using humour, laughing and joking with colleagues and dehumanising the patient by referring to the corpse as 'it'. While, dehumanising behaviours such as these may also result from embarrassment or simply not knowing how to act appropriately (Blum 2006, Weigal et al 2007), they are nonetheless, perceived by patients and carers as insensitive and indicative of poor quality care (Rogers et al 2000; Woods et al 2000).

There have been persistent claims that nurses need to be supported to overcome their fears in dealing with death and dying in clinical situations (Field and Kitson 1986; Williams and Field 2002) and that this should ideally occur during undergraduate pre-registration education (Hurtig and Stewin 1990, Kiger 1994, Beck 1997). It has been acknowledged that an individual's personal knowledge and experience of death may enhance or detract from their ability to provide care to others depending on how they have dealt with that experience (Allchin 2006). It is thus essential that educational programmes encourage nurses to learn from their own experiences.

Impact of education on nurses' attitudes and anxiety

Despite an increasing amount of death education in nursing programmes, students and newly qualified nurses claim that their training does not adequately prepare them to deal with death and dying (Aulino and Foley 2001, Mallory 2003, Caton 2006, Brajtman 2009). Writing 20 years ago, Hockley (1989) felt that student nurses were not prepared for dealing with dying patients and their relatives. Hockley found it very hard to decide how to best provide the teaching that nurses needed but concluded that it was possible to teach nurses how to effectively look after dying patients and bereaved relatives and even to deal with their own grief.

A decade later, Ferrell et al (2000) conducted a study involving 2333 registered nurses to determine the most common concerns experienced by nurses about EOL care. Nurses were asked to rate how well different aspects of EOL care were taught in their formal training. Aspects rated included pain assessment, pain management, symptom management, psychological support for patients, attention to spiritual needs and bereavement support. While the majority of nurse respondents (89.5%) felt that EOL content in basic nurse education programmes was important, almost two-thirds (62%) rated the overall content on EOL care as inadequate. Less than a third rated their grief, bereavement and spiritual support to patients at EOL as

effective; pain and symptom management education was also perceived as being inadequate.

Experienced registered nurses agree with this view (Tyree et al 2005, Wallerstedt and Andershed 2007). For example, in Tyree et al's (2005) survey of registered nurses (n=607) with different educational qualifications and from a wide range of practice settings, 72% had not had any EOL course or learning during formal training. Other inadequacies reported in nurse education include pain management, symptom management and overall content on EOL care (Arber, 2001; White et al 2001, Tyree et al 2005).

Similar findings have emerged from more recent research. Studies by Wessel and Rutledge (2005) and Hopkinson et al (2005) also found that nurses felt inadequately prepared to care for dying patients. Hopkinson et al's (2005) qualitative study explored the experiences of 28 newly qualified nurses working in acute medical wards in England. The study found that a number of participants were ambivalent about the usefulness of their EOL care education with particular comment made about training on communication. Most nurses considered their studies to be of little relevance to caring for the dying and seemed unaware of the ways it was supporting their practice. They believed it was experiential learning rather than formal pre-registration education that most helped them to care for dying people. Nonetheless, effective communication has been highlighted in strategy documents as a particularly important skill in EOL care (RCN 2002, DH 2008).

Weigal et al's (2007) study found that nurses' attitudes and anxiety had no correlation to level and type of education. Nor were there differences between nurses who had clinical experience of dying patients while still in nursing school and nurses who did not. Their survey of 154 registered nurses who worked in different clinical settings found that males in particular, were more anxious and apprehensive about dealing with death and EOL care than females. Individuals with less nursing experience also scored higher on apprehension. This is consistent with other studies which suggest that experience in caring for dying people does not guarantee skill proficiency or positive attitudes (Cooley, 2000; Kurz and Hayes, 2006; Malloy et al, 2006, Barrere et al 2007).

A recent study by Schlairet (2009) provides further evidence that pre-registration education fails to adequately equip nurses for EOL care. This cross-sectional survey of nurses (n=567) explored the competencies and prior education of nurses working in a variety of health settings in the US. This research identified shortfalls in knowledge, skills and attitudes for the competent delivery of EOL care. Yet recognition of the importance of these attributes in nursing is not new.

Calls for support and skills

A number of studies suggest that not only is training inadequate but so too is the level of available support. Students are not provided with enough support to cope with experiences related to death and dying (Beck 1997, Loftus 1998, Caton 2006). Nursing students placed in clinical situations where they will encounter death need support if they are to pass safely through this transition stage in their entry to the nursing profession (Hopkinson et al 2005). Caton (2006) calls for continuing educational opportunities for nurses to develop competence and feelings of control. She also advocates for the careful selection of mentors for newly qualified nurses.

Kurz and Hayes (2006) argue that support can be developed through education provision that enables students to confront their personal attitudes towards death anxiety and end of life issues in order that they can help their patients do similarly in relation to their own death. This is echoed by Brien et al (2008) who argue convincingly that an affective learning strategy is the most effective way of achieving this. While skills are usually defined by gaining cognitive knowledge and psychomotor techniques, affective learning combines a process of critical thinking and self-questioning. Both students (n=137) and educators in Brien et al's (2008) evaluation of an intensive 4-week mandatory course found the experience challenging. The authors conclude however, that affective learning activities positively influence the development of compassionate nursing interventions with students gaining a new understanding of their own and patients' attitudes and anxieties. The affective domain within EOL curricula is especially significant, however, as recognition of the importance of feelings, values and beliefs that influence behavioural responses alongside core practical clinical competencies of treatment and care giving.

Key points

Findings from this literature review highlight the following four key points:

- Awareness of the importance of EOL care education within the pre-registration nursing curriculum is increasing.
- Patients' and carers' perspectives on what constitutes quality care point to the importance of communication. While nurses see communication skills as central to EOL care education, the priority for patients is being treated as individuals with non-verbal elements such as sensitivity and warmth especially valued.
- Despite an increasing amount of death education content in pre-registration nursing curriculum, newly qualified and experienced nurses do not consider that they are adequately prepared to deliver EOL care.
- There is insufficient support for both students and newly qualified nurses to help them cope with the practical and emotional experiences related to death and dying.

Conclusion

The death of a patient is an experience which most nursing students will face. Nurse education, currently based within the university sector offering both diploma and degree level qualifications, has adopted a more holistic approach to EOL care. Provision is now focused towards a life-course perspective that includes experiences of death and the social context of dying. Despite these developments, the evidence from patients, carers and students still suggests that EOL training varies in its effectiveness and fails to adequately prepare nurses to deliver EOL care. Effective communication was an important factor in judging the quality of care received (Woods et al 2000, Johnston and Smith 2006) with modules on communication skills featuring heavily within EOL nurse education (Dickinson et al 2008). While the contribution of patients to the design and delivery of EOL care education is a topic beyond the focus of this discussion, it may be an area for future research.

Given evidence of the difficulties nurses experience in dealing with death, especially those working in non-specialist EOL care settings such as general hospitals, it is reasonable to ask whether we can ever adequately prepare nurses to deal with death. The in-depth death education that underpins the specialist training of palliative

care nurses suggests that it is. It has been suggested that with appropriate support and knowledge this is an area of nursing, in the general acute context as well as in the palliative context, that can be rewarding and fulfilling. Nurses have reported feelings of happiness and generosity in their relationships with dying patients and their families, citing this as highly stimulating and satisfying work (Wallerstedt and Andershed 2007, Schlairet 2009).

The concern over quality of care and increasing numbers of elderly and frail people, many of whom will require long term care in institutional settings, may act as the imperative to continually shape the nurse education curriculum with a stronger focus on EOL care. It is this category of dying people for whom palliative care has not hitherto been available that may, in the future, be the beneficiary of greater levels of EOL care education within both pre and post-registration nurse training programmes.

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