Student nurses learning about death, dying and loss: too little too late?

How to cite:

For guidance on citations see FAQs.

© 2014 Baywood Publishing Co., Inc.

Version: Accepted Manuscript

Link(s) to article on publisher’s website:
http://dx.doi.org/doi:10.2190/IL.22.4.c

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.
Student nurses learning about death, dying and loss: too little, too late?

Joyce Cavaye, The Open University, and Jacqueline H Watts, The Open University in London

Abstract

Concerns about the care provided to people dying from life-threatening illness have prompted a number of international reforms to improve the quality of palliative and end-of-life (EOL) care. The majority of this care is provided by nurses. They spend more time with dying patients than any other health professionals and therefore, need specific clinical skills and knowledge. Palliative and EOL care education is increasingly being positioned as a specialism, available only to a small number of registered nurses as part of continuing professional development. However, increasing numbers of patients with life-threatening illness are being treated in non-specialist settings by nurses with a generalist education. Furthermore, undergraduate nurse education has traditionally had a limited focus on palliative and EOL care, hence claims that undergraduate nursing curricula are inadequate. Drawing on an international literature, this review explores the evidence about the adequacy of undergraduate curricula in this area. It considers the extent to which palliative and EOL curriculum is included in undergraduate nurse education and draws upon evidence from students and registered nurses, who as consumers of education report feeling unprepared to care for and communicate with, dying patients.

Key words: end-of-life education; palliative care; student and nurse perspectives; undergraduate nurse education

Introduction

Despite death being a universal human experience, the subjects of death and dying continue to be taboo in many countries (Chan et al, 2014). As a consequence, quality enhancement of healthcare is not routinely extended to the process of dying. Due to the emergence of palliative care as a recognised speciality, the work of preparing for a “good death”, though now more readily incorporated into some areas of clinical practice, falls mainly outside the dominant medical model that has cure as its focus (Schneiderman and Jecker, 2011). Although a majority of people in western societies currently die in hospital, death and dying is not seen as part of the hospital’s core business (McGann, 2013: 19). In this setting, death is considered only from the perspective of the living not from the dying, with death now largely invisible within hospital spaces (McGann, 2013). Death in this context is indicative of the idea of medical failure. It is as a reaction to this way of death, that the hospice movement emerged with its holistic and open approach to death as a fundamental principle of palliative care. Attention by healthcare professionals to the physical symptoms of terminal disease and to the associated mental distress is what marks out palliative care (Watts, 2010).
Access to high quality palliative care by everyone with life-limiting illness is incorporated within the World Health Organisation’s (WHO) policy agenda (WHO, 2002). Increasing longevity (particularly in western countries) and the experience of many living with long term chronic illness, means that there is an increased capacity for greater numbers of people to benefit from palliative care if introduced earlier in the disease trajectory. Thus the future setting of much long term palliative care is more likely to be in the community in people’s homes, with only a small proportion of palliative care patients receiving care in clinical spaces such as hospitals and hospices (McGann, 2013). This relocation of care points to a community care approach with palliative care increasingly the responsibility of district nurses (Burt et al, 2008). This development is set against a background of increasing specialisation of palliative care education available to only a small number of doctors and nurses as part of post-registration training.

A wider but related concern is that nurses, as part of their undergraduate nurse training, receive only limited palliative care education and report being unprepared to deal with the death of patients and provide support to bereaved families (Deffner and Bell, 2005). This is a complex area requiring cultural competence as well as specific skills to negotiate the medical environment surrounding EOL (Cui et al, 2011). Given the growing demand for palliative care that aims to prevent unnecessary distress in dying by focusing on ‘whole-person care’, nurses with only limited training in issues connected to death and the processes of dying is problematic – both for them and their patients. Nurses report that the most common competency missing in their training is learning how to talk to patients and families about dying (White et al, 2001). Whilst communication skills are a required competency within nursing practice, it is also seen as central to preparation for a ‘good death’.

Drawing on findings from an integrative review that explored published literature reporting on death education within nurse education, this discursive analysis argues for palliative care to become a generalist rather than a specialist clinical skill for all nurses as part of their qualifying education programmes. The article proceeds in five parts. The first section provides further context for the review highlighting a range of international policy initiatives aimed at improving EOL care. Some of these policies specifically acknowledge the need for greater emphasis on palliative and EOL care within undergraduate nurse education. The second section discusses the implications of policy development for undergraduate nurse education. This is followed by a brief section that outlines the methodology used for the integrated literature review. The first of the discussion sections considers the nature and extent of palliative and EOL education provided to nursing students and highlights significant disparities in the amount of teaching devoted to this topic. The second discussion section focuses on the nature of this education as perceived by students and qualified nurses and the impact of palliative and EOL education on their experience of dealing with death in clinical practice. This is followed by a discussion on communication skills within undergraduate curricula and the impact these have on the quality of care delivered. The article concludes with a summary of key discussion points
together with commentary on the possible future direction of palliative care education within nurse education.

**Policy developments**

In recent years there has started to emerge increased attention on the experience of death from the perspective of both dying people and those who care for them. This has been due mainly to the increased profile of palliative care among healthcare workers and the public, often as part of public health initiatives that are concerned with issues of accountability and quality. As a consequence, we have seen the development of policies in many countries aimed at the delivery of high quality EOL care.

Providing high quality palliative care for dying patients and their families is incorporated within the World Health Organisation’s (WHO) policy agenda (WHO, 2002). This agenda essentially seeks to change the culture around EOL care to ensure that all individuals facing a life-limiting illness have access to high quality care services when facing death. The WHO (2012) estimates that 36 million deaths in 2008 were due to non-communicable diseases, such as cancer or cardiovascular disease. The majority of these patients die without adequate pain or symptom control and most lack access to psychological and spiritual support (Paice et al, 2008; Radbruch et al, 2012).

As a response to WHO directives, there has been a growth in the development of policies in many countries aimed at improving access to, and the quality of, palliative and EOL care. For example, in Europe, a Task Force on the Development of Palliative Care was founded in 2003 under the auspices of the European Association for Palliative Care (EAPC) with the aim of generating and disseminating an evidence-based repository of inter-professional palliative care (Centeno 2006). The United States (US), Ireland and Australia have all focused on the development of care standards (Institute for Clinical Systems Improvement, 2009; Irish Hospice Foundation, 2009; Palliative Care Australia, 2009).

A further example of policy development is provided by Canada, where policy now underpins structural change in service delivery and sets out a wide ranging agenda to achieve quality outcomes for palliative care patients regardless of the care setting (Health Canada, 2007). Meanwhile, the goal of the national palliative care development programme implemented in France, is to develop home and hospital palliative care services that includes a focus on education for all health care workers (Hirsch, 2009). More recently, the Prague Charter echoes the WHO directive by urging governments around the world to implement health care policies that “will ensure the relief of suffering through adequate access to patient-centred palliative care wherever it is needed” and that “failure to provide palliative care can constitute cruel, inhumane or degrading treatment” (Radbruch et al, 2012: 101). Other countries such as the UK have however, placed a greater emphasis on improving the quality of EOL rather than palliative care and published the End of Life Care Strategy in 2008 (Department of Health, 2008).

**Implications for nurse education**
A common theme underpinning these policy developments is the need to enhance educational provision about death and dying to inform care practice. This is regarded as being central to the success of these policy initiatives. The Prague Charter, for example, acknowledges the need for changes in the undergraduate curricula for all health care professionals to ensure that within their training, they acquire a basic knowledge of palliative care and are, therefore, better equipped to deliver it (Radbruch et al, 2012). In the UK the End of Life Strategy claims that nursing staff are not provided with education in this area as healthcare managers often fail to recognise that providing care for dying patients is one of their core functions. It thus advises that care of the dying should be embedded in nurse education at all stages of the career trajectory (Department of Health, 2008). Similar developments in the USA have also focused on quality enhancement of EOL care. For example, the End-of-Life Nursing Education Consortium (ELNEC) in America was established in 2000 in order to improve EOL expertise in educators teaching on undergraduate nursing programmes (Ferrell, 2005; Paice et al, 2008).

These educational initiatives reflect an international trend whereby palliative care that has been associated with cancer, now focuses more widely on other conditions such as multiple sclerosis, dementia and motor neurone disease (Addington-Hall and Higginson, 2001; Paice et al, 2008). Thus, while the majority of people in western societies continue to die in hospital (Gomes and Higginson, 2004; 2008), death and dying is not seen as part of the hospital’s core business (McGann, 2013:19). Moreover, increasing demand has created a policy directive that care should be provided in a range of settings which includes the community.

This policy shift towards community home-based palliative care is set against a background of increasing specialisation of palliative care education available to only a small number of doctors and nurses as part of post-registration training (Brueckner et al, 2009; Lynch et al, 2010; Mutto et al, 2012). As a consequence of these educational initiatives, palliative and EOL care is now positioned as a specialist and elitist area with an increasing number of continuing professional development modules available (De Vlieger et al, 2004; Skilbeck and Payne, 2005).

As a result of this specialism and relocation of care, family doctors and nurses, with generalist clinical training, are delivering EOL care without specialist knowledge and skills in this area (Burt et al, 2008; Dickinson, 2007; Lynch et al, 2010; Phillips et al, 2010; Shipman et al, 2008). This situation is incongruous given that the main aim of international policies referred to above, is to influence healthcare practice to ensure that everyone approaching the end of life experiences a ‘good death’.

It is estimated that the majority of patients dying from like-threatening illness do not experience a ‘good death’ (Ferrell et al 2005; Paice et al 2008). This reflects negatively on the adequacy of their undergraduate education with further evidence of this coming from nurses who report being unprepared to deal with the death of patients and ill-equipped to provide support to bereaved
families (Mallory, 2003; Deffner and Bell, 2005; Barrere, 2008). This is a complex area requiring cultural competence as well as specific skills to negotiate the clinical medical environment surrounding EOL (Cui et al, 2011).

Nurses, as part of their undergraduate training, receive only limited education on death and dying. Yet, caring for dying patients is not an optional part of nurses’ role. They typically spend the most time with dying patients and provide physical and psychological care throughout the lifespan and in a variety of healthcare settings. They need therefore, to be competent in clinical and interpersonal skills in order to provide care to patients facing life-threatening illness and death in a variety of settings whether that is hospice, hospital or community. Given the growing demand for palliative care that aims to prevent unnecessary distress in dying by focusing on ‘whole-person care’, nurses with only limited training in issues connected to death and the processes of dying is problematic – both for them and their patients. It is imperative that all undergraduate nursing curricula make adequate provision for effective EOL education. This is the empirical and policy context of the discussion that follows.

Methods

The aim of the original integrated literature review on which this article draws was to contribute to knowledge about the efficacy of palliative care and EOL education in undergraduate nursing curricula. The review used an integrative approach, which according to Russell (2005) helps researchers to maintain a knowledge base in a particular area of practice or research. It offers a strategy to search for and assess what is known about a particular topic with a view to identifying central issues in a particular area or suggesting directions for future research (Russell, 2005). An integrated review of the literature is defined by Cooper (1998: 47) as one where “past research is summarised by drawing overall conclusions from many studies”. By systematically analysing and summarising the literature, an integrated review can identify gaps in current knowledge and the need for further research (Russell, 2005). In order to enhance rigour in the review, the five stage approach proposed by Whittemore and Knafl (2005) was used. The stages are: problem identification, literature search, data evaluation, data analysis and presentation of results.

For the purposes of this article, the key methodological dimension for discussion is that of the literature search. Sampling the literature is essential to enhance rigour in an integrative review (Whittemore and Knafl, 2005). For the original literature search, key terms included ‘student nurse’, ‘death and dying’, ‘end of life care’, ‘palliative care’, ‘nurse education’, ‘pre-registration’, ‘death education’ and ‘undergraduate curricula’ and combined Boolean search terms ‘and’ and ‘or’. The search was extended to include the terms ‘nursing communication’ and ‘communication nurse education’. The search explored eight electronic databases: ONCL First Search, ASSIA, PsychInfo, CINAHL, MEDLINE, EMBASE, British Nursing Index and AMED and was recently extended and updated by scanning reference lists of located papers for
pertinent articles and by hand searches of the most recently published editions of key journals.

The search was limited to papers written in the English language and published between 1985 and 2013. The review also used inclusion and exclusion criteria to select relevant literature. Inclusion criteria were papers reporting on primary and secondary research relating to: student nurses, undergraduate modules, death education, end-of-life, palliative or cancer care. Grey literature and best practice reports were excluded.

The authors of this article independently scrutinised the title and abstracts of each article. Papers which were deemed to meet the inclusion criteria were read and checked again against the inclusion criteria. Decisions were discussed and agreement reached on the final selection of articles to be included. From a possible 226 articles identified, 47 met the inclusion criteria and were included in the review. These articles originated from the UK, USA, South America, Canada, Australia, Europe, Scandinavia and SE Asia.

Three themes emerged from the analysis: the extent of palliative care and EOL education included in undergraduate curricula; student nurses’ views on their feelings and preparedness to care for dying patients and their families; and registered nurses’ perspectives on the adequacy of their education. An overarching theme was the issue of communication. The following sections provide a discursive analysis of these themes. The discussion does not address curricula content, teaching strategies and outcomes of educational provision, which have been discussed in detail elsewhere (Cavaye and Watts, 2014).

Death education in undergraduate nursing programmes

The literature suggests that education is an important element in preparing nursing students for palliative and EOL care. It has also been identified as being the most significant factor affecting nursing students’ attitudes toward care of dying patients (Frommelt, 1991; Barrere et al., 2008). Yet, reviewers of undergraduate education for nurses have, for more than three decades, consistently cited inadequacies of provision (Quint, 1967; Aulino, F. and Foley, K.2001; Cunningham et al, 2006; O’Conner and Fitzsimons, 2005; Mooney, 2005; Johnson et al, 2009) in terms of the amount of palliative care and EOL education delivered.

Initial evidence of inadequacy comes from an analysis of nursing textbooks and is strengthened by studies from across the globe that explores curricula content. For example, Ferrell et al’s (1999) analysis of 50 undergraduate nursing textbooks, found there was only minimal content on issues related to EOL care with only 2% of texts addressing this topic (Ferrell et al., 2000). In addition, a number of studies have found that the majority of nursing programmes do not have a dedicated or elective module on palliative or EOL care (Barrere et al., 2008), preferring instead to integrate content throughout other modules (O’Connor and Fitzsimmons, 2005; Ramjian et al, 2010; Dickinson, 2012). Thus the current literature review has revealed that in undergraduate nursing curricula, the focus on palliative and EOL care is
minimal and inconsistent and that training is neither adequate nor appropriate (Mooney, 2005; Barrere et al., 2008; Johnson et al., 2009).

Nonetheless, the evidence from other countries reveals more widespread coverage than previously reported. In the United States of America for example, only 3% of 311 nursing programmes surveyed had dedicated courses on EOL content in their curricula (Wells et al., 2003) and an average of less than 14 hours was spent on end of life issues (Dickinson et al., 2008). An improvement was found by a more recent study by Dickinson (2012) whereby of 408 nursing schools surveyed, 86% now included EOL curriculum (Dickinson, 2012). While in Canada, 96% of nursing programmes offer ‘death education content’ with an average of 24 hours provided as classroom tuition and 36 in clinical practice (Downe-Wamboldt and Tamlyn, 1997).

In the United Kingdom a mean of between 7.8 and 12.2 hours was spent on teaching about EOL (Lloyd-Williams and Field, 2002). However, a more recent survey of 66 UK undergraduate programmes found the average number of teaching hours dedicated to palliative and EOL education has increased to an average of 45 hours (Dickinson et al, 2008). While this suggests a positive improvement, this provision is often ‘squeezed in’ to an already overcrowded curriculum (O’Connor and Fitzsimons, 2005; Dickinson et al, 2008: 167).

In Australia, from 26 undergraduate nursing programmes surveyed, only 8% (n = 2) allocated more than 20 hours, while 48% (n = 12) allocated 5–10 hours of teaching to EOL care (Johnson et al., 2009). These findings suggest that there has been little change to the provision of death education in undergraduate nursing curricula over the last 50 years (Johnson et al, 2009). It appears that in South American countries such as Argentina, there is virtually no palliative or EOL education in the undergraduate nursing curricula (Mutto et al, 2012).

The literature discussed above provides emerging evidence that global efforts to increase the amount of death education in undergraduate nurse education are underway. However, despite this evidence, students and qualified nurses claim that their training does not adequately prepare them to care for dying patients and their families (Dickinson et al., 2008; Brajtman 2009; Ramjan et al., 2010; Peterson et al, 2013).

**Student and nurse perspectives**

In recent years there has started to emerge increased attention on the experience of death and dying from both the perspective of dying people and those who care for them. This has been due mainly to the increased profile of the service user movement which seeks to ensure that the model of user as consumer is firmly entrenched within healthcare. Since students and registered nurses can be considered users and consumers of education, it is pertinent to take account of their perspectives.

Of all healthcare professionals, nurses spend the most time with patients and their families and are uniquely placed to enhance the quality of care provided. It is therefore, essential that nurses learn to deal with death so they can be effective practitioners, gain job satisfaction while alleviating stress and
burnout. For many undergraduate nursing students however, caring for dying patients is a challenging and anxiety provoking prospect (Leighton and Dubas, 2009) and is reported to be a common fear when entering nurse education programmes (Loftus, 1998; Mutto et al, 2012).

At the start of their training, when anticipating possible encounters with dying patients, students express feelings of dread, helplessness and anxiety (Loftus, 1998; Wong and Lee, 2000). They anticipate difficulties with the emotional care of dying patients, the pain of seeing them suffer, the shock of seeing a dead body and the difficulty of dealing with bereaved relatives (Beck, 1997; Loftus, 1998). On encountering their first death, students often have vivid recollections of it (Blum, 2006; Cavaye, 2009) and reported feeling sadness, anger and guilt (Beck, 1997; Loftus, 1998).

Caring for dying patients is a main source of stress during clinical placements (Beck, 1997; Wong and Lee, 2000; Gibbons et al, 2011). This is further evidenced by Mutto et al's (2012) survey of undergraduate students (n=680) that found whilst the majority felt at ease when in contact with terminally ill patients, almost 40% only wanted a short-lasting relationship with them. This was explained in terms of wishing to avoid having emotional involvement with patients. Only 3% of students had undertaken a palliative care seminar but 97% felt that death and care of dying patients should be part of their undergraduate curriculum. Whilst students in their final year of study had greater experience of caring for dying patients, they were also more likely than first year students, to say they did not feel adequately prepared. Other commentators have found that students’ strong emotional reactions to patient suffering can result in a degree of disengagement with subsequent avoidance of the patient and their family (Wass, 2004). Helping dying patients come to terms with their imminent death is highly demanding and stressful for students.

Allchin’s (2006) study also explored the impact of death on 12 student nurses providing care for dying patients during their rotation in adult nursing. 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 the studies reported above, 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 et al, 2009).

Further evidence of this need is provided by studies that report the experiences of qualified nurses as opposed to students (Hopkinson et al, 2005; Weigal et al, 2007). Ferrell et al (2000) for example, conducted a study involving 2333 registered nurses working in a variety of settings, to determine their most common concerns relating to EOL care. Nurses were asked to
rate how well different aspects of EOL care were taught in their formal training including 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.

Other studies confirm that these findings were not unique amongst experienced registered nurses (Tyree et al, 2005; Wallerstedt and Andershed, 2007). For example, in Tyree et al's (2005) survey of registered nurses (n=607) from a wide range of practice settings, 72% had not had any EOL education during formal training. These findings accord with those of Peterson et al (2013) whose small qualitative study with registered nurses (n=26) found that 66% said they had either no EOL education or felt they had inadequate training on the subject.

Similar findings have emerged from studies by Wessel and Rutledge (2005) and Hopkinson et al (2005) who also found that nurses felt inadequately prepared to care for dying patients. Hopkinson et al’s (2005) small qualitative study explored the experiences of 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 believed it was experiential learning rather than formal theoretical death education that most helped them to care for dying people. Other reported inadequacies in nurse education include pain management, symptom management and overall content on EOL care (Arber, 2001; White et al, 2001; Tyree et al, 2005).

Death anxiety has found to have no correlation to level and type of education (Weigal et al, 2007). Weigal et al’s (2007) 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 (Kurz and Hayes, 2006; Malloy et al, 2006; Barrere et al, 2007; Lange et al, 2008).

Research has also identified shortfalls in knowledge, skills and attitudes for the competent delivery of 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 and provides yet further evidence that undergraduate nurse education fails to adequately equip nurses for EOL care (Schlairet, 2009). Thus, despite the increase in death education and determined efforts made by educators (Paice et al, 2007; Dobbin, 2011; Bush, 2012), the evidence from students and registered nurses suggests that undergraduate death education remains inadequate.
Communication

A common theme underpinning the studies reported above, is the issue of communication, regarded as an essential skill for nurses and accorded a high priority within undergraduate curricula (Dickinson et al, 2008; Wallace et al, 2009). Open communication between healthcare professionals and patients who are reaching the end of their lives is seen as central to preparation for a ‘good death’, with this as a core principle of palliative care (Ronsen and Hanssen, 2009). However, a number of studies report nurses’ concerns about a lack of proficiency in communication skills particularly in the context of EOL care. Students have for example, expressed feelings of fear and inadequacy when communicating with terminally ill patients and comment on a lack of classroom preparation (Cunningham, 2006; Peterson et al, 2013). They are reported to find communication with dying patients and bereaved relatives challenging and feel more comfortable talking with them on a superficial level (Wong and Lee, 2000; Walsh and Hogan, 2003).

Nurses have also indicated that they would like more communication training focused specifically on caring for a dying patient and the family enabling them to provide clear information while being sensitive to the emotion of the situation (Peterson et al, 2013). According to Pfund et al, (2004) nurses’ distress arises, not so much from patients dying, but from their own self-perceived lack of communication skills. Since families are increasingly consulted on the care of their dying relatives, it is essential that nurses are able to provide them with information and resources as well as support.

Differences are reported between patients’ and nurses’ views about the importance of communication to quality of care. For example, in Johnston and Smith’s (2006) study of dying patients and registered nurses, nurses identified effective communication as a determinant of quality care. Patients however, did not accord communication the same importance, prioritising instead qualities such as kindness, warmth, compassion and genuineness, being treated as individuals and being supported to maintain independence and control over their lives. Patients valued nurses who provided emotional support, who spent time with them, who were ‘there for them’ and who were prepared to listen (Johnston and Smith, 2006).

These findings align with those of Woods et al (2000) whose small-scale study involved terminally ill patients and their carers, who judged the quality of care on the basis of its personal characteristics such as generosity with ‘private’ time and simple acts of kindness shown by nurses. Patients reported that ‘knowing someone was there’ was nurses’ most important contribution. These gestures, demonstrating nurses’ care and support, were highly valued by patients. Knowing when, how and what to communicate in relation to palliative and EOL care, is an essential nursing skill that all nurses should be competent in and not one that is developed only through post-registration continuous professional development modules.

Discussion and conclusion
This review draws on an international literature to explore the extent to which palliative and EOL education is included in undergraduate nurse education. It draws upon evidence from both student and registered nurses, who as consumers of education, report feeling unprepared to care for and communicate with, dying patients.

It is estimated that the majority of people dying from life-threatening conditions do not experience a ‘good death’; they die without adequate symptom or pain control, and the management of social, psychological and spiritual concerns (Radbruch et al, 2012). Recognition of this has led to recent policy initiatives on an international level, raising the profile of palliative and EOL care, with the aim of increasing access to and improving the quality of care provided to everyone experiencing life-limiting illness. Of all healthcare professionals, nurses are at the forefront of care provision across the lifespan and in almost all healthcare environments including inpatient, outpatient, home, community and hospice settings. Thus, nurses have an essential role in delivering this care and need to be equipped with particular knowledge and clinical skills.

The inadequacy of nurse education is, however, perceived as a barrier to achieving high quality palliative and EOL care (Allchin, 2006; Peterson, 2013), with this paucity first highlighted almost half a century ago by Quint (1967) in her seminal study. Undergraduate nursing curricula have traditionally had a limited emphasis on palliative and EOL care and there have been persistent reports of nurses feeling unprepared to care for dying patients (Cui, 2011; Mutto et al, 2012).

Consequently, there have been increases in the amount of palliative and EOL care in the undergraduate curricula. For example, the recent survey by Dickinson (2012) found that the 86% of nursing schools in the US now taught students about the experience of dying. In the UK, the average number of teaching hours dedicated to death education in the UK was 45 hours (Dickinson, 2008). This indicates a four-fold increase over the past two decades. In Australia, Argentina and Asia, a minimal and inconsistent approach to the inclusion of death education was indicated. There was little evidence in the literature of many other countries increasing the amount of death education in undergraduate curricula.

Anxiety about death and dying and personal attitudes towards EOL matters are shaped during nurses’ undergraduate education (Kurtz and Hayes, 2006). Leming and Dickinson (2007) consider whether familiarity with death reduces death anxiety amongst healthcare professionals who are routinely confronted with the reality of dying and its consequences. They argue that younger, less-experienced clinicians experience higher levels of death anxiety and are less comfortable with dying patients than longer serving colleagues (Leming and Dickinson, 2007). With the development of the hospice movement there have been increasing opportunities for health care professionals and patients to express these death anxieties and for educators to address them. This development is however, set against a wider cultural background that continues to view death as an extraordinary experience imbued with a sense
of mystery and dread. Thus, despite death being a universal human experience, the subjects of death and dying continue to be taboo in many countries (Chan et al. 2014).

Although we can only speculate to what extent this taboo has impacted upon nurse education, the fact remains that student and registered nurses perceive their training in both clinical and communication skills to be inadequate in preparing them to deal with dying patients. Although clinical skills to manage symptoms have come to be seen as an important component of a ‘good death’, the evidence suggests that communication skills are an essential factor in judging the quality of care received (Woods et al., 2000, Johnston and Smith, 2006). Effective communication can help to improve patients’ emotional and physical wellbeing throughout their illness and eventually enable them to have a ‘good death’.

The teaching of communication skills appears to be a key area where theoretical input combined with practice may increase students’ confidence and reduce their anxieties (Cunningham et al., 2006; Wallace et al., 2009). Promoting choice and offering psychosocial support to patients to help them cope with a range of losses require high levels of sensitive and empathic communication, which, if to be meaningful to patients, has to be responsive to them as individuals. While a high priority is now placed on these skills, this comes with little evaluation of its impact on patients.

The inadequacy of nurse education programmes is of particular concern for two key reasons. Firstly, palliative and EOL care is now positioned as a clinical specialism requiring advanced skills and available only to a small elitist group of advanced practice nurses as part of continuing professional development. This suggests that only a relatively small number of patients can receive care from a limited number of nurses with specialist training. Secondly, an increasing number of patients express a preference for dying at home rather than in an institutional setting and this has been supported by policy directives that seek to ensure more care is provided in the community. However, as a consequence of this relocation of care, nurses with a generalist clinical training are increasingly expected to deliver palliative and EOL care (Burt et al., 2008; Lynch et al., 2010; Phillips et al., 2010). This situation is untenable, given that the main aim of international policies is to ensure that all individuals approaching death should have access to high quality care.

Community based palliative and EOL care is complex, reliant as it is on a mixture of professional care and family presence (McGann, 2013). Changing public attitudes for a preference to die at home and the development of models of palliative care that are increasingly ‘home-based’ are two factors that create the imperative for palliative care to be a generalist as well as a specialist skill amongst the nursing workforce. Thus, we argue that it is essential that undergraduate education programmes equip all nurses with adequate skills and confidence to deal with death.

Given the reports of the difficulties many nurses experience in caring for dying patients in non-specialist care settings, it is reasonable to speculate whether
we can ever adequately prepare nurses to deal with death. One measure of effective death education provision is that cited by Dickinson (2007: 715) who argues that if “at the end of nursing school students feel comfortable educating the patient and family about the dying process, are ready to respond to patients who request assistance in dying, are ready to break bad news to a patient and family, then these professional programmes will have come a long way toward educating students about end-of-life issues”.

As a final comment, the shift from palliative care as a post-registration nursing specialism to becoming a core nursing competence on qualifying programmes may not be without its challenges. In recent years we have seen both nursing and medical careers develop on the back of specialist expertise in the field of palliative care. This may give rise in some quarters to resistance to the ‘democratisation’ of what is currently seen by some as an elite specialism best suited to advanced levels of clinical practice.

References


Deffner J, and Bell S. (2005) ‘Nurses’ death anxiety, comfort level during communication with patients and families regarding death, and exposure to communication education; a quantitative study’, *Journal for Nurses in Staff Development*, 21: 19-23.


Institute for Clinical Systems Improvement (2009), *Health Care Guidelines: Palliative Care*, Minnesota, Minn, USA.


