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End of Life and Palliative Care Issues in UK Pre-Registration,
Undergraduate Nursing Programmes

ABSTRACT

End of life and palliative care topics have traditionally not been in nursing school curricula. Only in recent years have these been included. The aim of this research was to determine the current status of such an emphasis in programmes in the United Kingdom (UK). A mailed survey in 2006 to the 66 undergraduate (pre-registration) nursing programmes in the UK (return rate of 79%) determined that end of life and palliative care play a significant role in these programmes. Forty-five teaching hours on average were devoted to these topics. All of the schools have some provision on end of life and palliative care, and over 95% of students participated in these courses. A nurse was usually the primary instructor, although non-nurses were sometimes used. Attitudes toward dying and death and communicating with terminally-ill patients and family members were emphasised. By highlighting dying and death in the curricula, nursing schools appeared to be giving nursing students an opportunity to face the issue of death, thus helping them to be better prepared to help their patients and their families to do so.

Key words: palliative care, end of life issues, UK nursing programmes, death and dying

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INTRODUCTION AND BACKGROUND

Quint's landmark study (1967) in the United States (US) on the education of nurses with dying patients highlighted the inadequacy of educational provision for nurses in this area of care. Since the 1960s communication and awareness about dying in modern western societies have been topics for debate, with a particular emphasis by health professionals to improve their communication with patients facing a terminal prognosis (Field & Copp, 1999). By the late 1970s and early 1980s, pre-registration, undergraduate nursing programmes in the United Kingdom (UK) had an emphasis on death education, yet it was somewhat limited. The full semester course, for example, was typically an elective with few requiring it. Webber in the UK (1989) pointed out that death education for nurses tended to focus on the practical and legal aspects of death, with little input on interpersonal skills, until the hospice movement came along. Field and Kitson (1986), in a survey of UK undergraduate nursing programmes, noted a mean of 9.8 hours related to death and dying-related topics. More recently, a survey of UK nursing programmes by Downe-Wamboldt and Tamlyn (1997) revealed a rather widespread coverage in that 96% offered "death education content."

Doyle (1987) reported that in the UK, despite the existence of death education content in many nursing programmes, students stated that their preparation to provide terminal care was inadequate. More recently, Cunningham and colleagues (2006), in a survey of 152 pre-registration students enrolled in diploma/degree nursing programmes, found that 78 percent perceived that they did not

have sufficient skills required to care for cancer patients during their placement experience.

Likewise in the US, offerings in end of life care have increased in nursing schools, yet in 1997 the US Institute of Medicine of the National Academy of Sciences identified large gaps in health care professionals' knowledge of strategies in dealing with patients' end of life issues (Aulino & Foley 2001). In examining end of life care and education for nurses over the past 20 years, researchers (Matza et al 2003; Mallory 2003) have systematically cited differences.

Death education has been in the curricula of UK nursing programmes for over a quarter of a century, yet the first introduction of the term "palliative nursing" was in 1989 by a specialist interest group of the Royal College of Nursing in England, the Palliative Nursing Group (Seymour 2004). Palliative care arose out of the change from acute to chronic causes of death and the emphasis of health care on improving quality of life (Higginson 1993). The notion that palliative care is synonymous with death education is apparent in many curricula, yet palliative care encompasses much more than care of the dying or nurses' attitudes toward death (Jodrell 1998). Jessica Corner (1994, p. 782) reported evidence that palliative care in nursing education curricula was being addressed, yet reports of students in programmes suggest that the benefits gained from such education is "very variable." Copp (1994) noted over a decade ago that advances had been made in identifying a body of palliative care knowledge to teach health care professionals, with progress particularly notable within nursing.

The World Health Organization (WHO) first defined palliative care in 1986, then updated the definition in 2002. The WHO defines palliative care (WHO 2007) accordingly: ". . . an approach

that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” The WHO definition was further refined by Sam Ahmedzai and colleagues at the University of Sheffield (2004, p. 2194) to better reflect the increasing multi-professional specialisation on this subject. Their recommendation is that palliative care be defined as follows: “Palliative care is the person-centred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimise the quality of life of patients and their families or close friends.”

The UK policy scene today is well established for health care, including end of life issues, through the National Institute for Health and Clinical Excellence (NICE) and the NHS Cancer Plan. NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health via public health, health technologies, and clinical practice. NICE also provides lists of cancer drugs and the pros and cons of such. The NHS Cancer Plan sets out a comprehensive strategy to address cancer and links prevention, diagnosis, treatment, care and research. Aims of the NHS Cancer Plan are to save more lives, ensure that cancer patients obtain the right professional care and treatment, address the inequalities in health, and build for the future through research.

More attention to end of life issues is given today, yet the amount of content that deals with the wide range of end of life care issues continues to be minimal (Walsh & Hogan 2003). There is

currently, for example, limited information on the preparation of pre-registered nursing students regarding their preparation for cancer care (Cunningham et al 2006). Yet, according to Mitka (2000), of all health professionals, nurses are in the most immediate position to provide care, comfort and counsel at the end of life for patients and families. Compared with other health care providers, nurses spend the most time with patients and their families at the end of life (Ferrell et al 1999). Nurses serve as advocates for patients with end-stage illnesses and their families, collaborate with interdisciplinary-care team members regarding patient outcomes, and provide nursing care based on patient care goals developed by working with the patient and family. Thus, nursing care of seriously-ill patients and their families is an important part of interdisciplinary, holistic, end of life care (Kirchoff et al 2003). Nurses, however, need to recognise and confront their own reactions to death before they can help their patients to do so (Hurtig & Stewin 1990).

Previous research, as noted above, suggests that progress is being made in better preparing nurses for relating to patients in the final days of their lives. For example, a recent study of nurses (Deffner & Bell 2005) concluded that those exposed to an end of life communication program felt more comfortable talking about end of life issues than those nurses not participating in such programs. There is evidence that education in palliative care can change health professionals' attitudes to palliative and terminal care (Vejlgaard & Addington-Hall 2005). Yet, studies are needed to assess current offerings in pre-registered nursing programs on end of life care, as Cunningham and colleagues (2006, p. 61) note: “. . . there appears to be limited research on the preparation of pre-registered nursing students in caring for cancer patients.” This study updates our knowledge on end of life and palliative care provisions in UK pre-registration, undergraduate nursing programmes.

METHODS

The aims of this study were reportorial in order to determine the current status of end of life offerings in UK pre-registration, undergraduate programmes. The following was sought:

1. the status of end of life and palliative care issues in UK pre-registration, undergraduate nursing programmes;
2. the background of the instructor(s);
3. the teaching methods and readings;
4. the percentage of students taking the course provisions;
5. the number of teaching hours on palliative and end of life care;
6. the percentage of students spending time with a hospice or palliative care patient;
7. the topics covered in the curriculum.

The Institutional Review Board for the Protection of Human Subjects (IRB) at the College of Charleston (US) had given approval for a similar study of nurses in the United States earlier in the year, thus the Ethics Committee at Lancaster University (UK) supported their decision for a similar study to be carried out in the UK.

A self-complete structured questionnaire was mailed to the 66 three-year pre-registration, undergraduate nursing programmes listed in the 2006 University and College Courses Directory in the UK in May of 2006 with two follow-up mailings. The three-year pre-registration programme in the UK is streamlined, when compared to the four-year baccalaureate programme in the US, yet the

programmes are similar. The two page questionnaire was designed to gather information on course provisions on palliative and end of life care. The survey was mailed to the dean/director of each of the nursing programmes, although someone other than that individual may have been delegated to respond to the survey. Such an inconsistency in who actually completed the questionnaire could give an uneven picture of end of life issues, since the professor, programme chair, or someone other than the dean/director might not have a complete picture of the issues in the particular nursing school and may thus be answering based on limited knowledge.

RESULTS

A total of 52 surveys (79%) were returned. All of the nursing schools had some provision on end of life and palliative care. The lecture was the most popular teaching method used in just over half of the schools (Table 1.). The overwhelming majority (95%) of students participated in the course provisions.

Table 1. about here

UK nursing schools sometimes took an interdisciplinary approach, although a nurse participated 100% of the time (Table 2.). Patients and carers, psychologists, and social workers were called upon the most by nursing schools to aid nursing faculty in teaching the end of life provision. The methods

Table 2. about here

of teaching included lectures, seminars, small group discussions and clinical case discussions (Table 3.).

Table 3 about here

Videos and films were used in about half of the programmes. Hospice visits occurred in three-fifths

of the programmes. Role play and the use of simulated patients were both utilised to some extent. Required reading tended to be “books and articles.” A few schools required only a textbook while some others relied solely on journal articles (Table 4.).

Table 4. about here

The average number of teaching hours for palliative and end of life care was 44.71. Of the 11 schools offering a full semester course, 76% of students took the course (eight programmes had 100% participation). Sixty-two percent (62%) of students spent time in a hospice or with palliative care patients.

Topics covered in the curriculum more than 90% of the time were: attitudes toward death and dying, communication with terminally-ill patients and their families, pain and symptom management, and grief and bereavement (Table 5.). Other items receiving high priority were the psychological, social and spiritual needs of the patient, thus, teamed with pain control, these concepts encompassed the idea of palliative care. Neonatal issues and palliative and end of life care in the global context received the least attention from the nursing schools. In responding to the survey, a number of programmes pointed out that neonatal issues were covered in their child nursing programmes, but not in their pre-registration education.

Table 5. about here

DISCUSSION

Pre-registration nursing programmes in the United Kingdom on end of life issues have progressed their end of life and palliative care undergraduate education since Field and Kitson (1986) published

their survey over 20 years ago. They reported an average of 9.8 hours spent on death and dying related topics; our 2006 study revealed an average of 44.71 teaching hours spent on palliative and end of life care. Such a finding is most favorable when compared to a 2005 study of 580 US baccalaureate nursing programmes which found an average of only 14 teaching hours on this topic (Dickinson 2006). With the introduction of palliative care into the curriculum of UK nursing schools in 1989, it appears that their efforts have been successful and palliative and end of life care are “alive and well” today in pre-registration, undergraduate education.

Less than one-fourth of the nursing programmes in this study offer a full semester provision on palliative and end of life care, one-third integrate a unit on the topic into another course(s), and a “lecture(s) in various courses” is being utilized in slightly over half of the schools. A comparison to 408 US undergraduate baccalaureate nursing programmes (Dickinson 2007) reveals less than one-fifth offering a full semester provision, slightly less than half integrating end of life issues into other courses, and slightly over half utilizing a lecture(s) in various courses. An entire course may not fit into current curriculum offerings. Integration into various aspects of the nursing programme may give the students a better overall exposure within a variety of venues. The lecture format is the most popular mode of teaching nursing students and certainly gives information regarding end of life issues.

The lecture format, however, is criticized by Patrick Hill (1995) who argues that the emphasis is on the *content* of the curriculum, while neglecting the process of learning. Hill suggests that the impediments to proper education in the care of the dying remain institutional as well as attitudinal.

On the other hand, a lecture-based course on end of life care, integrated with reflective exercises may prove to be useful, as noted with students at the University of Iowa's College of Medicine (US) (Rosenbaum, 2005). The exercises of self-reflection included visualizing their deaths, documenting their experiences with death, writing essays reacting to course content, and participating in small-group sessions. These activities allowed students to critically examine and discuss their experiences and concerns regarding end of life issues. Role-playing, incorporated into end of life provisions, occurred in one-third of the nursing programmes in this study, and the use of simulated patients in 14 percent of the programmes, gives students an opportunity to express their feelings through such interaction. Clinical case discussions, found in two-thirds of the programmes, and audio-visual materials, used in slightly over half of the provisions, can complement the strictly lecture mode. A lecture course can thus be augmented with activities into a didactic curriculum to promote student reflection, giving a foundation for students' caring for the dying.

A recent study of health care professionals, including nurses (Copp et al 2006), revealed that the educational input and experiences of working with patients with cancer were overall positive regarding the respondents' confidence, communication skills, decrease in anxiety and application of knowledge gained in the classroom to professional practice. The current study of UK pre-registration undergraduate nursing programs reveals that 96-plus percent include communication with terminally ill patients and family members (compared with 92 percent in the US study of 407 undergraduate baccalaureate nursing programmes by Dickinson 2007), suggesting that this high priority should enhance nurse-patient-family interactions. Also, hospice visits occur with nearly two-thirds of these nursing students. In addition, a study by Dunn and colleagues (2005) of

practicing nurses revealed that those who spent more time with families and/or dying clients had more positive attitudes than those with less exposure.

Much of the progress in end of life and palliative care issues in the nursing profession is likely contributed to various initiatives in the UK. The Calman-Hine report (Cunningham et al 2006) in 1995, for example, outlined a strategy for the delivery of quality treatment and care for cancer patients. This initiative has led to developments of nine cancer networks to optimise standards for the delivery of cancer care and to improve the experiences of cancer patients. The Royal College of Nursing (RCN 2003) report, entitled “A Framework for Adult Cancer Nursing,” recommended revisions to pre-registration education to accommodate the need for all nurses to have an awareness of the required knowledge and skills and attitudes and competence to provide both initial and ongoing care for individuals affected by cancer. In addition, the National Institute for Clinical Excellence in 2004 (Cunningham 2006) recommended national guidelines for the preparation of a portion of the workforce to provide palliative and supportive care services for cancer patients and their carers. Such a workforce for cancer care at the pre-registration level appears to be currently important, note Cunningham and colleagues. Recommended national guidelines include a much earlier exposure to patient care in practice and the acquiring of appropriate skills and competency outcomes at different stages of a student’s learning.

Other UK initiatives include the Gold Standards Framework (GSF) and the Liverpool Care Pathway for the Dying Patient (LCP). The GSF, a programme for community palliative care advocated by the NHS (Thomas 2003), has spread through the nursing profession as more and more nurses are

qualifying as palliative care nurses. As of 2005, for example, there were 8500 palliative care nurses in the UK (Clark et al 2006). GSF is used for individuals likely to be in the last 6 to 9 months of life and is to help plan care for these patients to make sure their possible needs are shared with others. Likewise, the LCP was developed to take the best of hospice care into hospitals and other settings. LCP is used to care for patients in the last days or hours of life, once it is known they are dying. The LCP involves prompting good communication with the patient and family and anticipatory planning including psychosocial and spiritual needs, symptom control and care after death (NHS EOLC Programme Progress Report 2006). The most frequently used individuals to teach the course provisions, other than nurses, are patients and informal carers. Who better to teach about end of life issues than the patient or carer? These individuals are certainly “on the front line” of end of life concerns.

Topics covered in nursing schools definitely highlight palliative care as key issues covered are pain and symptom management, spiritual, psychological, and social concerns of the patient. A description of palliative care nursing, provided by Lugton and Kindlen (1999), is that all life threatening illnesses have implications for the physical, social, psychological and spiritual health of both the individual and family. An approach to improving satisfaction for nurses with critical care patients would be to help nurses gain knowledge on end of life care (Kirchoff et al 2003). Nurses are in a unique position to deal with the patient after the medical doctor has delivered the prognosis.

“Attitudes toward death and dying” was the only topic, out of 19 topics, in which 100 percent of the programmes comply. The topic of attitudes toward death and dying was included in the curriculum

of 90 percent of 407 US undergraduate baccalaureate nursing programmes, according to Dickinson (2007). As previously noted, nurses need to recognise and confront their own reactions to death before they can help their patients. With *all* of the programmes in this study incorporating attitudes toward death and dying in their curricula, the need is certainly being addressed by the UK pre-registration, undergraduate nursing programmes. Good role models and mentorship support appear to have a positive influence in shaping students' development of self-awareness and maturity in practice and could be viewed as pivotal to students' learning and support in caring for patients with terminal illnesses (Cunningham et al 2006). Such benefits in practice placement within nursing education include team cooperation and thus help develop appropriate skills, attitudes, and behaviours.

CONCLUSION

The emphasis on end of life and palliative care in pre-registration, undergraduate nursing programmes in the UK appears to have progressed in the past 20 years. Hopefully, this momentum will continue to be important as we move through the 21st century. Being able to communicate effectively with patients at the end of their lives and with their families is a significant role that nurses need to fulfill. As reported here, nursing programmes are stressing the importance of communication, both with the patient and the family.

Nurses need to recognize and confront their own reactions to death before they can help their patients do so. Educators recognize that death anxiety and personal attitudes related to end of life issues are shaped during students' initial educational programs (Kurz & Hayes 2006). By addressing

attitudes toward death and dying, nursing schools are striving to help the nursing student personally face the issue of death. Our findings suggest that UK pre-registration, undergraduate nursing programmes on end of life and palliative care issues are headed in the right direction. Continued implementation should benefit students now and in the future.

At the end of nursing school, if 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 nursing programmes will have done their part in educating their students about end of life issues.

NEED FOR FUTURE RESEARCH

It is not known from our data whether a multidisciplinary approach to teaching end of life and palliative care issues is more effective than exclusively using a nurse as teacher. Such a project could be carried out by making the sole nurse-taught course provision as the control group, then making the multidisciplinary team approach the experimental group and evaluating accordingly. It would also be of value to assess the teaching methods used to determine which is best for presenting end of life and palliative care issues. In addition, an assessment of the content of these course provisions would be useful in finding a model for teaching end of life and palliative care issues. Additional research could determine geographical variation of responses and traditional versus new universities' emphasis on end of life issues (Our data did not allow such an analysis due to anonymity of our respondents.).

Exit interviews/surveys with graduates of pre-registration nursing programmes would be useful to determine these graduates' assessment of their preparation of skills to relate to patients with end stage illnesses and their families. Such an assessment could occur at the time of graduation, then again some five or so years later. The product that nursing schools are turning out is indeed these students. Some marketing research to "test the product" is in order.

Though our study only asked "What are the required readings on palliative and end of life care?," it could be beneficial to know what these readings are. A combination of books and articles was the most popular type of reading requirement, followed by journal articles only, then to a lesser extent "a textbook."

The data from this study prevent a breakdown of instructional methods by topic. It would be of interest to know which topics receive the greatest concentration in the time allowed for end of life issues. Noting that a particular topic is "covered" in the curriculum does not indicate the degree of coverage. Future research might address this topic, therefore giving a more complete profile of end of life issues covered in pre-registration, undergraduate nursing programmes in the UK.

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Table 1. Course provision on palliative and end of life care issues in UK nursing schools (in percentages)*

Full semester course	24
Unit integrated in another course	33
Lecture(s) in various courses	55

*Percentage totals more than 100 due to some schools checking more than one option.

N = 52

**Table 2. Nursing schools with end of life instructors from various professional backgrounds
(in percentages)**

Nurse	100
Patient/Service user	23
Psychologist	21
Social worker	15
Sociologist	10
Physician	10
Theologian	8
Philosopher	4
Attorney	4

*Others with less than 1 percent were: ethicist, bereavement counselor, and funeral director.

N = 52

Table 3. Teaching methods used in end of life provisions (in percentages)

Lecture	94
Seminar/small group discussions	88
Clinical case discussions	68
Hospice visit	59
Video/film	53
Role-play	34
Simulated patients	14
Funeral home visit	2

N = 50

Table 4. Type of required course reading on palliative and end of life care (in percentages)*

Books and articles	84
A textbook	13
Journal articles	30

*Percentages do not come out to 100 due to some schools checking more than one choice.

N = 50

Table 5. Topics covered in the curriculum on end of life issues (in percentages)

Attitudes toward death and dying	100
Communication with terminally ill patients	98
Communication with family members	96
Pain and symptom management	94
Grief and bereavement	92
Spiritual care at the end of life	86
Psychological aspects of dying	84
Social contexts of dying	73
Euthanasia	71
Policy issues in palliative and end of life care	63
End of life nutrition	61
Advance directives	61

End of life hydration	59
Quality of life assessment	59
Research in palliative and end of life care	55
Relating to patients with AIDS	49
History of hospice/palliative care	49
Neonatal issues	27
Palliative and end of life care in the global context	22

N = 52