



# Palliative care and end of life issues in UK pre-registration, undergraduate nursing programmes

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**Summary** Palliative and end of life 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 palliative and end of life 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 palliative and end of life 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.

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## Background

Nurses play a pivotal role in palliative and end of life care. It seems therefore logical that nursing school curricula should include these topics in their course provisions. In the UK pre-registration programmes for nurses consist of preparation to diploma or degree level. Typically nurses on either programme share and learn alongside each other

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for parts of the curriculum with the differences in levels generally reflected in the nature of the assessment. There are currently 66 higher education institutions in the UK offering pre-registration undergraduate courses for nursing students. So how prominent are palliative and end of life care issues within UK nursing school curricula?

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 and 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 accessing 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. 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 and Foley, 2001).

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). The WHO defines palliative care (Sepulveda et al., 2002) as: "...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 Ahmedzai and colleagues at the University of Sheffield (2004, p. 2194) to better reflect the increasing multi-professional specialisation of this subject. Their recommendation was 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, to optimise the quality of life of patients and their families or close friends". 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.

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). 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 was "very variable".

Just what is the health care policy regarding palliative and end of life issues to which graduates of these undergraduate nursing programmes will be expected to adhere? The UK health care policy is well established, including end of life issues, through the National Institute for Health and Clinical Excellence (NICE, 2004) and the NHS Cancer Plan (2000). A diagnosis of cancer does not imply an "end of life", yet cancer is a leading cause of death in the UK and palliative care may be required. Recently, Cunningham et al. (2006), in a survey of 152 pre-registration students enrolled in diploma/degree nursing programmes, found that 78% perceived that they did not have sufficient skills required to care for cancer patients during their placement experience.

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 evidence with regard to the use of effective therapies including drugs used to treat cancer. The NHS Cancer Plan (2000) sets out a comprehensive strategy to address cancer and links prevention, diagnosis, treatment, care and research. It aims to save more lives, ensure

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