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End-of-Life Issues in UK Medical Schools

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Abstract

Objective: A descriptive study to determine the current status of end-of-life (EOL) issues in UK medical schools. **Methods:** A brief questionnaire was mailed to the 31 medical schools in the United Kingdom in the spring of 2013. Data analysis consisted of frequency distributions. **Results:** All schools offered some exposure to the topic of dying, death and bereavement, and palliative care, although the orientation had increased somewhat from an earlier study in 2000. The palliative medicine specialist and the nurse specialist in palliative care are the most consistent members of the team. Most schools have hospice participation, with time spent with a hospice patient increasing over the period. **Discussion:** Data suggest that UK medical schools have addressed EOL issues. These findings should have significance for medical schools considering changes in their EOL offerings.

Keywords

end-of-life issues, UK medical schools, palliative medicine, hospice, death and dying

Introduction

End-of-life (EOL) issues in UK medical schools are increasingly playing a significant role in the curriculum. Back in 1968 the UK Todd Report on undergraduate medical education contained no reference to teaching about dying and death,¹ and it was not until 1980 that the Wilkes Report recommended a terminal care element be included in undergraduate medical training in the United Kingdom.² The Association for Palliative Medicine in Great Britain and Ireland later produced its curriculum in 1993.³ A brief review of the literature suggests that medical schools overall have not traditionally covered EOL issues very thoroughly. For example, Dyer⁴ and Bickel-Swenson⁵ point out the need for better education regarding EOL issues, including communication skills and palliative care. Likewise, Goldsmith and colleagues⁶ note that limited attention to palliative care communication training tends to be offered to medical students. Accordingly, as noted by a recent study in Iran, which suggested that physicians often lack the skills to communicate with patients and their families regarding EOL issues,⁷ such inadequacy is apparently widespread. Stollck said over a decade ago⁸ that the time has come for incorporating palliative care into the curriculum of medical schools and that compassionate care for dying patients includes a move from a curative model of care to a palliative model of care.

The profile of EOL issues has certainly been accentuated by the behavior of Dr Jack Kevorkian in the United States with his “suicide machine” in the 1990s, active voluntary euthanasia (AVE) becoming legal in some European countries and physician assisted suicide (PAS) legalized in a few states in the United States, all in the 21st century, proliferation of organ

transplants, advance directives, and ability of medical science to prolong life through artificial means resulting in an increase in deaths from chronic illness rather than acute illness. Such issues highlighted by the media have more or less forced medical schools to address EOL issues. Since 1975, the first author has surveyed the medical schools in the United States at 5-year intervals and was also involved in a survey of UK medical schools in 2000. The US findings suggest that medical schools have made significant strides in their EOL offerings since the 1970s.⁹ With the United Kingdom as one of the leaders in the world in palliative care and EOL issues, along with Canada and Australia, the United States, and most of Western Europe, the existence of similar programs in other parts of the world is very idiosyncratic.¹⁰ Thus, the authors sought to determine the current status of UK medical schools’ EOL offerings to ascertain changes, if any, over time.

Methods

In the spring of 2013, a brief questionnaire was sent via snail mail, respectively, to the 31 medical schools in the United Kingdom asking for information regarding their EOL

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Table 1. Methods Used in Teaching About Dying, Death, and Bereavement in United Kingdom Medical Schools, 2000 to 2013.

	2000 (%) ^a	2013 (%) ^b
Lecture	21 (88)	19 (95)
Clinical case discussions	23 (96)	18 (90)
Hospice visit	22 (92)	17 (85)
Seminar/small group discussions	23 (96)	17 (85)
Video/DVD	19 (79)	14 (70)
Role-play	22 (92)	10 (50)
Simulated patients	5 (21)	8 (40)

^aN = 24.^bN = 20.

curriculum offerings. For comparison purposes, to look for change over time, we compared the 2013 data to UK data from the 2000 study previously published.^{11,12} The names and addresses were taken from the Internet Web sites of the schools. Mailings were addressed to the deans of the medical schools, with 3 follow-up mailings after the initial mailing. The project received approval from the institutional review board.

Information sought in the questionnaire included extent of offerings on palliative care and death and dying, EOL topics covered in the curriculum, percentage of students participating, teaching methods used, professional background of the instructors, whether a terminally ill patient addressed the class, and extent to which students spend time with hospice patients (see attached survey in Appendix A).

No statistical analysis occurred, as this article was meant to be descriptive, and the percentages tend to speak for themselves. Although not the thrust of the article, we will make comparisons to an earlier UK study and 1 in the United States, which asked the medical schools some of the same questions.

Results

Response rate to the questionnaire was 65% (20 of 31). All schools offered some exposure to the topics of dying, death, and bereavement. When compared to the 2000 study of UK medical schools, the mean number of teaching hours reported in 2000 was 20 and in 2013 was 27. The percentage of medical schools offering death and dying as a separate course was 13 in 2000 and 20 in 2013. Those schools in 2000 covering the topic in only "1 or 2 lectures" numbered 13%, and in 2013 the percentage was slightly less at 10%. As a module of a larger course, percentages in programs were basically unchanged: 26 in 2000 and 25 in 2013. The option of "other" on the survey was popular, with the majority of programs noting that the offerings were "integrated throughout the curriculum" (including clerkships and clinical placements) in over 50% both in 2000 and 2013. In both time periods, all the students had some exposure to dying, death, and bereavement.

Teaching Methods

Teaching methods over the 13-year period did not vary significantly, with 1 or 2 exceptions (see Table 1). The lecture,

Table 2. Professional Background of Instructors in United Kingdom Medical Schools for Dying, Death, and Bereavement, 2000 to 2013.

	2000 (%) ^a	2013 (%) ^b
Palliative medicine specialist	24 (100)	20 (100)
Nurse specialist in palliative care	15 (63)	15 (75)
Physician/general practitioner	20 (83)	11 (55)
Ethicist	4 (17)	9 (45)
Theologian/minister	11 (46)	6 (30)
Nurse	3 (13)	5 (25)
Psychologist	7 (29)	4 (20)
Psychiatrist	10 (42)	3 (15)
Sociologist	6 (25)	3 (15)
Social worker	11 (46)	1 (5)

^aN = 24.^bN = 20.

hospice visits, seminar/small group discussions, clinical case discussions, and hospice visits continue to be primary means of socializing medical students to EOL issues. The 2 areas where changes occurred are role-playing (dropped from 92% to 50%) and the use of simulated patients (doubled in exposure from 21% to 40% over the 13-year period).

Professional Background of Instructors

The multidisciplinary team approach continues to be the mode of presenting material to medical students in the United Kingdom (see Table 2). The palliative medicine specialist is involved in 100% of the programs in both 2000 and 2013. Of the 9 other professionals represented, 6 decreased in participation over the time period while 3 increased. The largest drops in participation were with general practitioners (83%-55%), psychiatrists (42%-15%), and social workers (46%-5%). On the other hand, the professional background of instructors, which increased the most over the 13 years, was ethicists (17%-45%).

Exposure to Dying Patients

Schools were asked whether a terminally ill patient addressed the students and/or whether the students had a relationship with such a patient that extended for several days or weeks. In 2 of the schools, both in 2000 and in 2013, hospice participation was not part of the medical curriculum. In all, 29% of the respondents in 2000 stated that a terminally ill patient addressed the class, and 35% in 2013 so stated. In 2000, 92% of the programs included hospice participation as part of the curriculum, whereas in 2013, 90% participated. When asked the "greatest extent to which students spend time with hospice patients," 37% in 2000 visited a hospice patient for "at least a few hours" and 37% "for a day or longer." Thirteen years later, participation had increased with 55% visiting for "a few hours," yet about the same percent (35) spent time from a day to a period covering several weeks. When asked whether the students have a continuing relationship with a patient with a terminal illness, 24% of the schools in 2000 so indicated (although not all students had such exposure) and 73%

Table 3. Mode of Delivery for Palliative Care Education in United Kingdom Medical Schools, 2000 to 2013.

	2000 (%) ^a	2013 (%) ^b
Separate course	7 (29)	5 (20)
Module of a larger course	6 (25)	6 (30)
Covered in "1 or 2 lectures"	1 (4)	1 (5)
Other (primarily scattered in curriculum)	10 (42)	8 (40)

^aN = 24.^bN = 20.

answered in the affirmative of those schools answering the question (11 of 15) in 2013. Of the schools so participating, 91% of the students in 2013 are involved in the "continuing relationship."

Palliative Care

When asked whether palliative care is offered in the curriculum, all of the UK medical schools in both 2000 and 2013 answered in the affirmative. Palliative care was offered as a separate course in less than 30% of the programs in both 2000 and 2013 (see Table 3) but tended to be more frequently presented throughout the curriculum, although a module of a larger course was also popular. The least popular way of presenting the topic was in "1 or 2 lectures." The average number of teaching hours for palliative care in 2013 was 26.9 (not available for 2000). All students participated in the palliative care offerings in 2000 and 2013.

Topics Covered in the Curriculum

End-of-life care topics were presented to each school to determine the extent of their coverage on these issues (see Table 4). Of the 19 topics listed, 80% or more of the schools in both surveys included the following in their curriculum: attitudes toward death and dying, communication with dying patients and their family members, grief and bereavement, social contexts of dying, psychological aspects of dying, analgesics for chronic and cancer pain, symptom relief in advanced terminal disease, and death certificates. Topics least covered in both time periods were physical therapy, neonatal issues, and relating to patients with AIDS. Most of the topics changed very little over time, with the exception of euthanasia, which dropped from 89% to 65%.

Discussion

Overall, EOL issues in UK medical schools continue to be emphasized in their curricula offerings. Although already including EOL issues in 2000, the schools represented in data here are having even better coverage in 2013. All of the schools are offering something on death and dying and palliative care in both time periods. Average number of teaching hours in death and dying increased from 20 to 27 over the 13-year period, as compared to only 14 and 17 hours, respectively, in US medical

Table 4. End-of-Life Topics Covered in the Curriculum of United Kingdom Medical Schools, 2000 to 2013.

	2000 (%) ^a	2013 (%) ^b
Attitudes toward death and dying	24 (100)	20 (100)
Communication with dying patients	21 (89)	19 (95)
Analgesics for chronic pain	23 (96)	19 (95)
Analgesics for cancer pain	23 (96)	19 (95)
Communication with family members of dying patients	23 (96)	18 (90)
Symptom relief in an advanced terminal disease	24 (100)	18 (90)
Grief and bereavement	22 (92)	17 (85)
Psychological aspects of dying (eg, anxiety, depression)	22 (92)	17 (85)
Death certificates	20 (83)	17 (85)
Social contexts of dying (eg, family care)	21 (89)	16 (80)
The experience of dying	19 (79)	16 (80)
Advance directives (living will, health care power of attorney)	18 (75)	16 (80)
End-of-life hydration	16 (67)	15 (75)
End-of-life nutrition	14 (58)	13 (65)
Religious and cultural aspects of dying	16 (67)	13 (65)
Euthanasia	21 (89)	13 (65)
Relating to patients with AIDS	9 (37)	4 (20)
Physical therapy	8 (33)	3 (15)
Neonatal issues	8 (33)	3 (15)

^aN = 24.^bN = 20.

schools in similar time periods, 2000 and 2010.⁹ As the concept "palliative care" was only coined in the 1970s, the United Kingdom has certainly been a leader in this field and in hospice over the years.

Separate courses on dying and death do not seem to be the direction that UK medical schools are following. A similar pattern was found in US medical schools from 2000 to 2010 with a separate course in dying and death in approximately one-fifth of the programs (18% and 21%, respectively, in 2000 and 2010), although separate courses in palliative care increased from 10% to 19% over the same time period.⁹ These topics in the United Kingdom tend to be scattered throughout the curriculum in most schools both in 2000 and in 2013. Overall, most US medical schools also favor integrating EOL issues throughout the program in existing courses or clerkships, rather than creating a new course devoted strictly to this subject matter.¹³ Thus, United Kingdom medical schools tend to be following the recommendation of Horowitz and colleagues¹⁰ to integrate these offerings into existing courses.

The lecture format and small group discussions/seminar approach continue to be popular as are clinical case discussions within the classroom setting. Regarding palliative care research endeavors in medical schools, "spotty didactic classroom exposure alone offers little benefit, whereas more extensive coursework and practical experience, including role-play and observed interactions with real and simulated patients, impart both meaningful change and learner satisfaction."^{10(p7)} A similar format of offerings with lectures mixed with seminars and

clinical case discussions was found in US medical schools in 2010 with some three-fourths and above preferring such.⁹ However, with the scattering of these offerings throughout the curriculum, classroom work and clerkships provide exposure to EOL issues. For example, hospice visits are found in 85% or more of the schools, thus exposure beyond the classroom setting. Accordingly, hospice visits increased from 43% to 60% of US medical schools between 2000 and 2010, yet far below the percentage in the United Kingdom.⁹ This emphasis on hospice involvement is occurring in the United States, although not as rapidly as in the United Kingdom.

If limited to classroom lectures and small group discussions/seminar format, that which might be missing is the unique individualization of each of us, especially when confronted by an approaching death situation, with its accompanying anxiety and the possibilities of pain and suffering, according to Mermann¹⁴ who taught "Seminar on Seriously Ill Patients" at the Yale University School of Medicine beginning in 1986. Addressing the question of whether or not medical students can be instructed in EOL issues, a study of general surgery residents from Brown University (Providence, Rhode Island) concluded that it is "possible to instruct in EOL and palliative care in an efficient and positive manner with lasting effects."^{15(p1806)} Supporting Mermann's assertion, the Brown University study found that by creating a curriculum based on the current literature with an emphasis on active participation, they were able to effectively teach EOL and palliative care in a useful way. Integration of classroom work and interaction with patients having terminal illnesses should be an excellent formula for addressing EOL issues in medical schools.

A multidisciplinary team approach is the mode of presenting the material in the curriculum, with the palliative medicine specialist a key player in all of the schools reporting both in 2000 and 2013. As noted, from the medical field, the general practitioner and psychiatrist were not pivotal players within the medical profession in 2013, as they were earlier. The ethicist was more involved in the curriculum in 2013. It appears as if the palliative medicine specialist is assuming more of a role in EOL offerings, as he or she is involved 100% of the time, thus perhaps less of a dependence on other medical doctors. The social worker has almost ceased to play a role, according to the responses in the survey in 2013. So, today, the palliative medicine doctor appears to be the steady performer, while other professionals play a lesser role, with the exception of the nurse specialist in palliative care and the ethicist. Such a team approach was concluded to be best also in clinical settings, according to a study of oncologists who agreed that patients with EOL illnesses should be treated in a multidisciplinary approach, with a group of specialists involved in treating these patients.⁷ Thus, a medical school model of interdisciplinary teaching could translate into clinical practice of interdisciplinary collaboration.

Regarding exposure to patients with terminal illnesses, about one-third of the schools in both time periods had such a person address a class, and over 90% of responding schools in both 2000 and 2013 included hospice participation in the curriculum. Thus, the changes there were minimal. Additionally,

when asked whether the students have a continuing relationship (for several weeks) with a patient with a terminal illness, those having such a relationship stayed unchanged (24% in 2000 and 25% in 2013 of the schools responding). Therefore, the overall level of exposure to patients with a terminal illness has basically remained unchanged over the interval.

Studies tend to confirm that exposure to individuals with terminal illnesses is positive for medical students. For example, Anderson and colleagues¹⁶ concluded from surveys of medical students graduating from the University of Pittsburgh (Pittsburgh, Pennsylvania) that those with personal or professional experience with death had more positive attitudes and higher knowledge scores, regarding helping dying patients and their families than those not having such experiences. Accordingly, from surveys of 262 senior-year students at 6 US medical schools,¹⁷ support was found for the development of formal curriculum on EOL issues and emphasized the importance of clinical exposure to terminally ill patients to prepare these graduates to provide quality EOL care. A study¹⁸ of Yale University medical students concluded that working with patients on EOL issues was well received in the acute inpatient setting. Setia and Watson¹⁹ noted evidence of the educational benefits of exposing medical students to hospice patients and practices and developed a service-learning elective where first-year medical students were trained as hospice volunteers. In a study of 166 first-year medical students before and after exposure to hospice,²⁰ a significant change in attitude was noted after the observational experience. Thus, exposure to individuals with terminal illnesses seems to have merit for medical students. The UK medical schools are indeed exposing their students to patients with EOL issues, an important contribution in an already crowded curriculum.

Like death and dying offerings, palliative care is presented in all of the UK medical school curricula in both 2000 and 2013, with 100% of students participating. Average number of teaching hours in 2013 was 27, compared to only 12 hours in US medical schools in 2010.⁹ As with death and dying offerings, palliative care has a tendency to be integrated throughout the curriculum, rather than in a separate course. Likewise, separate courses in palliative care were offered in less than 20% of US medical schools in 2010,⁹ compared to less than 30% in the United Kingdom in 2013. Studies have shown^{21,22} that introducing medical personnel to palliative care, particularly hospice, helps to protect the patient from ineffective interventions near the EOL and assists the patient and family in making educated decisions regarding treatment options. Palliative care tends to be associated with EOL issues, yet a move is on, especially in the United Kingdom, to not restrict palliative care to EOL but to endorse it as integral to the care of all seriously ill patients.¹⁰ The first author of this article noted such an emphasis back in 1990 when interviewing Dame Cicely Saunders, founder of the modern hospice movement.

Topics covered in the curriculum of each of the responding medical schools revealed little change over time, with the exception of euthanasia, which dropped from 89% of schools to 65%. Such a change could be a reflection of the limited return rate in 2013 with not all schools represented, as was the

case in 2000, or since active euthanasia is not legal in the United Kingdom, perhaps there is less of a tendency to work this topic into an already crowded curriculum. With the controversy around euthanasia in the United Kingdom in recent years, however, one would think that the opposite turnaround would have occurred. Also, more medical schools in 2013 are using an ethicist than in 2000, thus it would seem likely that more of an emphasis on this ethical issue would occur. The 3 areas queried with very limited coverage in UK medical schools in 2013 were physical therapy, neonatal issues, and relations with patients with AIDS. Physical therapy would not particularly be a responsibility of most medical doctors nor would neonatal issues, both being dependent on the specialty area of the doctor. With patients with AIDS in the United Kingdom more controlled through medication and education today, this topic would not be as significant for medical doctors in the 21st century, with the exception of infectious disease doctors.

United Kingdom medical schools seemingly are giving a good beginning to medical students by coping with EOL issues through interaction with dying patients. The exposure to these situations, however, has not changed much in the 13-year period under observation. This limited change is likely contributed to an already crowded medical curriculum with little room to expand. United Kingdom medical schools tend to be covering very important topics related to dying patients and their families. A significance of these findings is the usefulness for various medical school programs seeking to tweak their EOL offerings. Rather than “reinvent the wheel,” a curriculum committee can see what other programs emphasize regarding EOL issues and can thus adapt these offerings to their own curriculum. Studies cited here note that EOL offerings enhance a student’s ability to deal with EOL situations. These changes should make EOL issues more tolerable for the patient, the family of the patient, and the medical student, soon to be medical doctor—a winner for all parties involved.

Appendix A

Survey on End-of-Life Issues for UK Medical Schools

1. Name of medical school _____
2. What is the greatest extent to which dying, death and bereavement is represented in your curriculum?
 - _____ Covered in a separate course
 - _____ Forms a module of a larger course
 - _____ Covered only in 1 or 2 lectures
 - _____ Other, please specify _____
 - _____ Not taught formally
 If “yes,” total amount of teaching hours? _____
3. What percentage of your students participate in the dying, death and bereavement program before graduation? _____
4. Do you address the topic of palliative care in your curriculum? _____ Yes _____ No
 - If “yes,” greatest extent?
 - _____ Palliative care is covered in a separate course
 - _____ Palliative care forms a module of a larger course
 - _____ Palliative care is covered only in 1 or 2 lectures
 - _____ Other, please specify _____
 - _____ Palliative care is not taught formally
 - If “yes,” total number of teaching hours? _____
5. What percentage of your students participate in the palliative care program before graduation? _____
6. What are the teaching methods used in the dying, death and bereavement offering? (check as many as are appropriate)
 - _____ lecture _____ seminar/small group discussions _____ video/film/DVD
 - _____ role-play _____ simulated patients
 - _____ hospice visit _____ clinical case discussions
7. What is the professional background of the instructor(s) of your dying, death and bereavement offering?
 - _____ attorney _____ nurse _____ philosopher
 - _____ physician _____ psychologist _____ psychiatrist/physician
 - _____ social worker _____ sociologist _____ theologian/clergy
 - _____ other, please specify _____
8. Does a terminally-ill patient address the class? _____ Yes _____ No
9. Does the student have a continuing relationship with a terminally-ill patient?
 - _____ Yes, for several days _____ Yes, for several weeks _____ No relationship

10. What is the greatest extent to which your students spend time with hospice patients?

- ☐ Visit a hospice patient(s) for "a few hours"
☐ Visit a hospice patient(s) for at least two days
☐ Visit a minimum of a week with a hospice patient(s)
☐ Visit a hospice patient(s) over a period of several weeks
☐ Other, please specify _____
☐ Hospice participation is not part of the medical curriculum

If "yes" to any of the above, what percentage of your students participate? _____

If hospice is not currently part of your curriculum, do your future curriculum or clinical plans include hospice participation? ☐ Yes ☐ No

11. Which topics are covered in your curriculum?

- ☐ attitudes toward dying and death
☐ communication with dying patients
☐ communication with family members of dying patients
☐ grief and bereavement
☐ social contexts of dying (eg, family care)
☐ psychological aspects of dying (eg, anxiety, depression)
☐ religious and cultural aspects of dying
☐ the experience of dying (eg, pain, anxiety)
☐ analgesics for chronic pain
☐ analgesics for cancer pain
☐ symptom relief in an advanced terminal disease
☐ end-of-life hydration
☐ end-of-life nutrition
☐ physical therapy, please specify _____
☐ neonatal issues
☐ relating to patients with AIDS
☐ euthanasia
☐ advance directives (living will, power of attorney for health care)
☐ death certificates

Your name and title (optional) _____

We would appreciate your enclosing a syllabus or reading list for your course(s) on dying, death and bereavement and/or palliative care or any related course. My e-mail contact is dickinsong@cofc.edu. Thank you. George Dickinson

Any comments? _____

Declaration of Conflicting Interests

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