

## Professional education in end-of-life care: a US perspective

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In 1997 a report from the Institute of Medicine (IOM) of the National Academy of Sciences identified large gaps in knowledge of care at the end of life which demanded attention from biomedical, social science and health service researchers. The report, *Approaching Death*<sup>1</sup>, clearly indicted healthcare professionals' lack of education about end-of-life care as a major barrier to improvement of services. The seven recommendations, summarized in Box 1, addressed various decision-makers and deficiencies. Among the fundamental elements of sound professional preparation for end-of-life care the institute listed: command of relevant scientific and clinical knowledge; mastery of technical, communication, interpersonal and other skills; appreciation of ethical and professional principles of care; and development of organizational skills to help patients and families navigate the healthcare system. The report stressed that, although these elements emphasize knowledge and skills, they also reflect a concern for the attitudes, values and feelings that shape and infuse their application.

This American perspective expressed in the IOM recommendations is not dissimilar from published international recommendations. The Expert Task Force of the World Health Organization, in its 1990 publication *Cancer Pain Relief and Palliative Care*<sup>2</sup>, called on governments to ensure that healthcare workers are adequately trained in palliative care and the relief of pain and recommended that palliative-care courses be an obligatory part of the basic training and certification of healthcare workers. These sentiments were echoed in Recommendation 1418 of the 1999 Parliamentary Assembly of the Council of Europe, 'Protection of the Human Rights and Dignity of the Terminally Ill and Dying'<sup>3</sup>. In the Council's view, one factor threatening the fundamental rights of terminally ill and dying patients was a lack of continuing education and psychological support for professionals working in palliative medicine. The Council recommended that member States be encouraged to develop and implement standards for high-quality training. In short, there is growing international advocacy for professional education in end-of-life care.

The United States' efforts to improve education in end-of-life care consist of a series of initiatives focused on: undergraduate, graduate and continuing education; faculty development; and a series of overarching efforts, such as the development of palliative care associations, programmes in distance learning and website networks. These approaches, directed at reducing the barriers for healthcare professionals, are briefly described in the following sections. They

### Box 1 Recommendations from the Institute of Medicine's *Approaching Death* (Ref. 1)

- 1 People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skilful and supportive care
- 2 Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms
- 3 Because many deficiencies in care stem from system problems, policymakers, consumer groups, and purchasers of healthcare should work with healthcare practitioners, organizations, and researchers to:
  - (a) Strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them
  - (b) Develop better tools and strategies for improving the quality of care and holding healthcare organizations accountable for care at the end of life
  - (c) Revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care
  - (d) Reform drug prescription laws, burdensome regulations, and State medical board policies and practices that impede effective use of opioids to relieve pain and suffering
- 4 Educators and other health professionals should initiate changes in undergraduate, graduate and continuing education to ensure that practitioners have the attitudes, knowledge and skills to care well for dying patients
- 5 Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research
- 6 The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care
- 7 A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families and the obligations of communities to those approaching death.

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represent a wide range of efforts at various stages of development, and their impact on professional education cannot yet be assessed—and still less the impact on care for the 2.5 million Americans who die each year. Concurrent efforts to transform the culture of death in America and eliminate institutional, economic and social barriers are also underway.

### UNDERGRADUATE EDUCATION

The IOM report commented on how little medical students are taught about end-of-life care. Billings and Block have outlined fifteen principles for undergraduate palliative care education including training as a professional responsibility, key content areas and evaluation methods<sup>4</sup>. Several schools (e.g. Harvard Medical School and Columbia) have developed special programmes for medical students fostering clinical experience, including rotations in hospice and palliative care units, along with course work electives<sup>5,6</sup>. Fleischman and Fins, through the New York Academy of Medicine, have devised an intervention tool to assess palliative care curricula and a peer review process for improvement. They have piloted this assessment in New York State's 14 medical schools, where palliative care is now being incorporated in the curriculum<sup>7</sup>.

The National Board of Medical Examiners, which examines medical students after their second and fourth years of training, have expanded the number of questions in their exams concerning pain and symptom management, palliative care and end-of-life care issues. Although medical schools are not yet mandated to develop curricula in end-of-life care, these initiatives and model programmes represent a promising trend.

### GRADUATE EDUCATION

Several initiatives have been launched to address the complaint that young medical graduates (residents) may have little exposure to dying patients and/or no opportunity for hospice rotations. The American Board of Internal Medicine (ABIM), in seeking to improve internal medicine residency and subspecialty training in end-of-life care, has focused on issues of professionalism, communication and evaluation<sup>8–11</sup>. In a survey of 55 ABIM-approved residency programmes, residents were asked to identify their level of competence in pain management, symptom control and communication skills with dying patients<sup>12</sup>. Although 74% felt competent in pain management, only 61% felt competent in talking with a dying patient—in discussing what his or her death might be like. Less than 31% felt confident talking to a dying patient who might wish to hasten his or her death.

To address these deficiencies, the National Internal Medicine Residency Curriculum Project has been mounted

to train residency directors and chief residents who, in turn, will become trainers at their own institutions in end-of-life care. The project includes training opportunities for over 180 internal medicine programmes. This effort is linked to an educational resource centre, the End-of-Life Physician Education Resource Center, whose role is to provide instructional and evaluation materials and serve as a central repository for peer-reviewed educational materials and information [[www.eperc.mcw.edu](http://www.eperc.mcw.edu)]. Both these initiatives are directed by Dr David Weissman at the University of Wisconsin, Milwaukee.

Since graduate education in the USA is heavily influenced by the subspecialty academic societies, a major step towards reforming residency education has been the adoption of core principles for end-of-life care by a substantial number of these societies<sup>13</sup>. Seventeen societies and the Joint Commission on the Accreditation of Healthcare Organizations have adopted policies that embrace the core principles. Agreement on these care principles has had major implications for the acceptance of the term palliative care in specialty-based organizations, many of which are now working to develop clinical methods, tools and guidelines to meet the needs of dying patients. At the same time they are addressing the need for professional education on these aspects of care.

A national consensus conference on Medical Education for Caring at the End of Life, in 1997, brought together 69 medical educators from various subspecialties who made the following four recommendations to improve education in palliative care: (1) the Liaison Committee on Medical Education should include a requirement that all medical students demonstrate competence in end-of-life care as a condition of medical school graduation; (2) the residency review committees, primary care specialties, and all other specialties in which there is significant contact with dying patients would set minimum standards for faculty training in end-of-life care and for resident experiences in care of dying patients, and, to ensure competency, programme directors should require that residents are directly observed while interacting with dying patients and their families; (3) medical specialty boards should integrate end-of-life care into their examinations; and (4) public and private funding sources, including the National Institutes of Health, should be encouraged to support programmes that train faculty, so as to meet the shortage of faculty trained in end-of-life care<sup>14</sup>. A series of consensus papers have indicated how the various medical subspecialties can educate their members<sup>4,15–20</sup>.

### Fellowship training in palliative care

About nineteen programmes in palliative care offer fellowship training [[www.capcmssm.org/fellowship.html](http://www.capcmssm.org/fellowship.html)], sometimes in cancer centres, sometimes in the palliative

care services of general hospitals. The American Board of Hospice and Palliative Medicine has created a task force to develop specific requirements for such fellowship training programmes and fellowship certification, with the goal of subspecialty certification in palliative medicine.

### **Faculty development programmes**

Clearly, faculty has great potential to advance educational and clinical care services as well as research on end-of-life care. The Veterans Administration Faculty Leaders Project [[www.va.gov/onn.flp](http://www.va.gov/onn.flp)] is a two-year initiative in which faculty leaders develop end-of-life and palliative care curricula to be used in training of resident physicians. The four aims of this project are to develop benchmark curricula and training strategies; to integrate curricula into thirty VA internal medicine residency programmes; to increase the number of internal medicine faculty leaders and innovators; and to make available specific curricula to VA-affiliated internal medicine residency programmes. Since one out of seven Americans die in the care of the VA system, the development of palliative care education within this healthcare delivery system is critical.

Two university-based faculty development programmes are Harvard Medical School Center for Palliative Care's programme of Palliative Care Education and Practices [[www.hms.harvard.edu/cdi/pallcare/](http://www.hms.harvard.edu/cdi/pallcare/)] and the Stanford Faculty Development Program in End-of-Life Care ([www.stanford.edu/group/SFDP/eolcare.html](http://www.stanford.edu/group/SFDP/eolcare.html)). They train physician and nurse educators in both clinical practice and teaching methods of interdisciplinary palliative care; they also offer instruction in developing and managing institutional programmes.

The Project on Death in America Faculty Scholars Program is a foundation-funded faculty development initiative. To date, it has funded 78 physicians and nurses who have been identified as outstandingly committed to improving end-of-life care [[www.soros.org/death](http://www.soros.org/death)]. The programme's aim is to promote the visibility and prestige of such clinicians and to enhance their effectiveness as academic leaders, role models and mentors.

### **Continuing medical education**

The American Medical Association has developed a Compassionate Competent Care Initiative to ensure that practising physicians are equipped with the knowledge and skills to provide the best possible care for dying patients. This includes the wide dissemination of a train-the-trainer curriculum, Education of Physicians in End-of-Life Care (EPEC), consisting of four thirty-minute plenary modules and twelve forty-five-minute workshop modules [[www.epec.net](http://www.epec.net)]. The EPEC listserv also allows individuals who

have trained in EPEC, or have an interest in end-of-life care, to communicate informally via e-mail.

The American Academy of Hospice and Palliative Medicine has created a curriculum consisting of twenty integrated, clinically oriented, self-contained self-instructional modules. They are designed for use by practising physicians, residents and medical students in academic centres and in hospice and palliative care programmes.

Various subspecialty groups, including the American Academy of Neurology, the American College of Surgeons and the American Society of Clinical Oncology, have sponsored programmes on palliative care at their national meetings. In addition, the American Academy of Neurology and the American Society of Clinical Oncology have surveyed their memberships on end-of-life issues<sup>21,22</sup> and have published consensus statements on the role of these specialties in palliative care<sup>23,31</sup>.

Several national centres have developed to focus attention on education, research and policy development, including the Center to Advance Palliative Care at Mount Sinai School of Medicine [[www.capcmssm.org](http://www.capcmssm.org)], the Duke Institute on Care at the End of Life [[www.iceol.duke.edu](http://www.iceol.duke.edu)], and the RAND Center to Improve the Care of the Dying [[www.rand.org/health.dying.html](http://www.rand.org/health.dying.html)]. In addition, numerous journals have been started—both in print and online—to provide peer-reviewed information on palliative care.

### **Physician certification**

The American Board of Hospice and Palliative Medicine has developed a palliative care certification programme [[www.abhpm.org/default.htm](http://www.abhpm.org/default.htm)]. The eligibility criteria require that a physician be licensed and certified by an American Board of Medical Specialties approved board or equivalent. Currently, there are 779 board-certified physicians in palliative care, most of them coming from internal medicine and family practice.

### **Nursing education**

A national initiative focused on nursing education is the End-of-Life Nursing Education Consortium [[www.aacn.nche.edu/el nec](http://www.aacn.nche.edu/el nec)]. Its major goals are to develop a core of expert nursing educators, to coordinate national nursing efforts in end-of-life care and to facilitate dissemination of a train-the-trainer programme for registered nurses.

Other efforts include the development of both a Nursing Leadership Consortium and a Nursing Leadership Institute on End-of-Life Care. The Consortium was organized to draw up a coordinated professional nursing agenda. The Institute was created to advance this agenda by increasing the leadership capacity of nurses; this initiative is creating a system of support networks and mentorships and has already led to development of a centralized Internet resource site run by Sigma Theta

Tau International [www.palliativecarenursing.net]. There is also a National Board for Certification of Hospice and Palliative Care Nursing [www.hpna.org/nbchn/index.htm] which has certified some 7000 hospice and palliative care nurses<sup>24</sup>.

### Education for social workers

The need for educational programmes for social work leadership is increasingly recognized<sup>25</sup>. Efforts in this arena include the Project on Death in America's Social Work Leadership Award, which to date has funded 23 individuals. These social work leaders are charged with developing initiatives between schools of social work and clinical practice in order to advance the role of social work in improving end-of-life care.

### Paediatric palliative care education

The Compendium on Pediatric Palliative Care has developed guidelines for care, or *Universal Principles*, agreed on by a large multidisciplinary international group of experts. This widely disseminated document can be ordered via the NHPCH website [www.nhpco.org]. Children's Hospice International [www.chionline.org/pacc.html] facilitates conferences, publications and web resources; the Academy of Hospice and Palliative Medicine has released a UNIPAC on paediatric palliative care; the *Oxford Textbook of Palliative Medicine* includes sections on palliative care for children; and various books are available for professionals<sup>26–28</sup>. Yet at present there exist no programmes specifically for paediatric palliative care certification.

### HIV/AIDS

Most palliative care monographs have focused on the cancer population. In October 2000, UNAIDS released a technical report, *AIDS: Palliative Care* [www.unaids.org/publications/documents/care/index.html], which strongly endorsed the importance of palliative care in caring for patients and families affected by the AIDS epidemic.

The National Pediatric and Family HIV Resource Center is a non-profit educational centre educating professionals who care for children and families with HIV and AIDS [www.pedhiv aids.org]. The National Institute of Allergy and Infectious Diseases has issued an important document entitled *Enhancing Supportive Care and Promoting Quality of Life: Clinical Practice Guidelines* [www.niaid.gov/default.htm]. However, for adult patients with HIV/AIDS, no specific guidelines exist at present for HIV/AIDS or hospice care except the UNAIDS document *AIDS: Palliative Care*. New York State guidelines exist for AIDS care in nursing homes and various day programmes, and numerous publications and curriculum developments address specific needs of patients

with AIDS at the end of life<sup>29–37</sup>. The François-Xavier Bagnoud International Pediatric HIV Training Program has commendably trained nearly 120 doctors, nurses, social workers, and other healthcare professionals from around the world in the care of children with HIV/AIDS [www.fxbcenter.org].

### THE FUTURE OF PALLIATIVE CARE EDUCATION IN THE USA

Although education in palliative care has made clear progress, it has yet to be incorporated fully into the fabric of medical education. Philanthropic support has spearheaded the initiatives, but programmes will only be sustained if they become an integral part of undergraduate and graduate training and continuing medical education. Continued funding of these initiatives and curriculum integration require the support of medical school deans and faculties, as well as State and federal resources. Since patients and families are calling for such care and the wider public see palliative care as a priority, there is hope that the reforms in medical education will continue. But these are only the first steps in institutionalizing palliative care in the USA.

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