Incorporating Palliative Care into Primary Care Education

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A national consensus is emerging that the general medical education of physicians for providing appropriate care to patients at the end of life and to their families is deficient.[1–11] Growing awareness of these problems in end-of-life care has stimulated many efforts to improve medical education.

In May 1997, the Project on Death in America and the Robert Wood Johnson Foundation funded a national consensus conference on medical education for care near the end of life. The conference organizers identified potential conference participants by soliciting nominations from leaders in palliative care and from professional organizations. The conference organizers, in collaboration with a multidisciplinary advisory committee, then honed the nominees to create a group representing key disciplines involved in the care of dying patients. Ninety-four academic leaders, representing a broad array of academic health centers and professional organizations, including representatives from the emerging field of palliative care ($n = 6$), as well as from internal medicine ($n = 14$), geriatrics ($n = 9$), psychiatry ($n = 9$), family medicine ($n = 6$), humanities, ethics, and social sciences ($n = 7$), medical education ($n = 6$), pediatrics ($n = 3$), emergency medicine ($n = 3$), neurology ($n = 3$), critical care ($n = 2$), oncology ($n = 3$), surgery ($n = 2$), obstetrics and gynecology ($n = 1$), and other fields ($n = 20$), participated in the meeting and the production of consensus documents.

All participants received background materials before the conference, including a status report on palliative care education,[1] a summary of recent research on palliative care education, and the summary of a series of focus groups of students and residents about end-of-life learning experiences. Participants met in plenary sessions and small working groups to develop a set of recommendations on how best to teach about care of dying patients and their families in various clinical and educational settings. Working groups were established in eight areas and focused on the same set of five questions about medical education: What are the opportunities for teaching about palliative care? What topics should be taught? What teaching approaches should we use? What institutional changes are necessary to facilitate this teaching? What are the unique opportunities and barriers for teaching about palliative care?

Each group developed recommendations to guide teaching about palliative care based on expert opinion and interpretation of the literature. Working group reports were prepared by the chairperson, with several iterations to include revisions, suggestions, and amendments from group members. The final reports were approved by all group members. This process is consistent with recent recommendations for the preparation of consensus documents.[12,13]

The Primary Care Working Group (one of several working groups) reflected the perspectives of many disciplines and brought into the discussion educational expertise and experiences from different vantage points (dean's office, community-based primary care education, managed care, educational development and evaluation, student affairs, and community-based consumer organizations).

OPPORTUNITIES FOR TEACHING

Overlap Between Primary Care and Palliative Care

The attitudes and competencies required to provide high-quality palliative care overlap substantially with those required to provide excellent primary care. Communication skills, understanding of the patient's "life world," commitment to comprehensive, integrated care of the patient and family, attention to psychosocial and spiritual concerns, emphasis on quality of life and maximizing function, respect for the patient's values, goals, and

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Developed for the National Consensus Conference on Medical Education for Care Near the End of Life, Washington, D.C., May 16–17, 1998.

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priorities in managing illness, providing care in the community, responding to cultural diversity, and collaboration with other professionals (including specialists) in providing care are core values and competencies for both primary care and palliative care, and thus should reinforce and strengthen each other. Many of these characteristics fall under the rubric of *relationship-centered care.*[14]

The Primary Care Physician in Palliative Care

Most physicians care for only 6 to 10 patients who die each year.[10] However, care of patients with chronic and life-limiting illness, the elderly, and the bereaved (5% to 9% of the population sustains the loss of a close relationship each year[15]) are common clinical tasks in primary care practice and are informed by an understanding of the principles and practice of palliative care.

Caring for dying patients is troublesome for many physicians.[16] Physicians in general, including primary care physicians, feel inadequately prepared to care for the dying.[17–19] Added emphasis on preparing primary care physicians for this role has the potential not only of improving the quality of care delivered to patients, but also of enhancing the professional satisfaction of physicians.

PALLIATIVE CARE CONTENT

Primary care physicians have a unique opportunity to practice and teach exemplary end-of-life care and to be role models for medical students and residents in mastering this demanding, but rewarding aspect of clinical practice. The following topics should be addressed.

Fundamentals of Palliative Care

Basic palliative care content for medical students and residents has been described.[20] Specific learning opportunities arise in the following areas:

- understanding and addressing the experience of physical, psychological, and spiritual suffering;
- communicating effectively and humanely with the patient and family about diagnosis, prognosis, treatment options, and goals of care;
- skillfully managing pain and other common, distressing symptoms commonly occurring in end-stage disease;
- providing accessible, high-quality home and hospice care, as well as other alternatives to acute hospital care;
- working with an interdisciplinary team to provide comprehensive, coordinated care to optimize quality of life using a range of both aggressive and palliative care options;
- understanding ethical issues in end-of-life care and respecting patients' personal values;
- recognizing and responding to cultural, linguistic, and spiritual diversity and to varied personal styles;
- recognizing and managing psychosocial and existential or spiritual distress and knowing when to refer patients for counseling related to these issues;
- educating patients and families about the processes of dying and bereavement;
- developing an awareness of one's own attitudes, feelings, and expectations regarding death and loss; and
- acknowledging and responding to the personal stresses of professionals working with dying persons.

Palliative Care for All Primary Care Patients

The primary care setting is also an excellent venue for addressing learning domains related to end-of-life care that are relevant to *all* primary care patients. Although much excellent teaching about negotiating treatment goals, maintaining comfort and optimizing quality of life, and the importance of attention to the meaning of illness to the patient and family takes place in general primary care settings, these concepts, which are applicable to the treatment of all patients, can be reinforced in teaching about palliative care. The following specific issues should be addressed:

- advance care planning and negotiating treatment goals for geriatric patients and those with a chronic illness;
- attending to pain and symptom control and optimizing quality of life for patients with chronic illnesses;
- breaking bad news to patients receiving new diagnoses as well as to patients whose prognoses are changing owing to disease progression;
- managing the fear and uncertainty associated with diagnostic tests for potentially serious illnesses;
- eliciting significant past experiences with illness and death and the impact of those experiences on the patient's expectations and fears about the dying process; and
- identifying opportunities for the fulfillment of personal goals in the midst of serious illness.

Understanding Death and Dying in the Community

Primary care physicians increasingly have a responsibility both to individual patients and to a panel of patients. An awareness of the epidemiology of dying in the community provides a valuable foundation for developing appropriate systems of care, initiating health promotion and disease prevention strategies targeted at particular causes of death in the community, and mobilizing community resources such as churches, civic groups, and schools to provide programs and resources related to death and dying for community members. The primary care physician can serve as an advocate for improved care of the dying in his or her community, as well as an educator of the public about care at the end of life. Students and residents benefit from having an opportunity to see primary care physicians in their roles as advocates for improved care and as public educators. In addition, they should be exposed to resources available in the community to aid the dying and their families.

Understanding Death as a Part of the Life Cycle

The primary care setting provides an opportunity for teachers to convey a respect for death as a normal part of the life cycle, rather than a "medical failure" as is conveyed in the "informal curriculum" of medical schools.[21] An appreciation of death as a natural event, and one that can be anticipated and talked about, paves the way for the learner to approach patients confronting the end of life with a therapeutic acceptance and awareness of unique possibilities for growth at the end of life.

Loss as a Model for Understanding and Dealing with Death and Dying

Students and residents working in primary care have extensive experiences with patients around the issue of *loss*. Most illnesses, and certainly all chronic illnesses and disabilities, entail an element of loss (e.g., loss of a limb, loss of function, loss of identity as a healthy person). Students and residents should learn the major conceptual models about how individuals deal with loss,[15,22–26] and should develop competence in assessing patients' coping with health-related loss and awareness of interventions available to help patients in the adaptation process.

Bereavement

Many primary care patients endure personal losses (of which death is only one) and seek medical attention from primary care physicians during the bereavement period for problems that may be related or unrelated to the loss. Common medical conditions related to bereavement are sleep disturbance, depression, substance abuse, and anxiety. Some patients will seek help for medical conditions during the time they are acutely grieving, and have the potential to benefit from physician intervention in the form of risk assessment for complicated bereavement and preventive counseling. Students and residents should learn about the health consequences of bereavement, develop competence in performing a risk assessment for complicated grief in the primary care setting, and learn about resources that can provide further help for grieving families (e.g., social work, chaplaincy, support groups).

Teaching about Ethical Issues at the End of Life

In contrast to the ethics learning that takes place on inpatient services, the opportunities to learn about ethics in the primary care setting are generally less dramatic and less crisis oriented. The primary care setting is an ideal one in which to learn and practice ethical behaviors that can *prevent* clinical and ethical dilemmas at a later point in the patient's illness.[27] Discussion of patients' values and preferences for care, communication about difficult prognostic information and treatment options, and exploration of sources of suffering and approaches to their amelioration offer the primary care educator an opportunity to model excellence in preventing end-of-life ethical dilemmas.

Teaching Interdisciplinary Teamwork

The primary care setting is an excellent environment for modeling teamwork and collaborative patient care among physicians, nurses, social workers, chaplains, and family and community members. Students and residents should be exposed to individuals in other disciplines as key collaborators in the care of patients at the end of life. They should have the opportunity to participate in clinical team meetings, to share care with other health professionals, and to make conjoint patient visits. Finally, students and residents should have experiences in which patients and family members provide their perspectives on end-of-life care issues.

PALLIATIVE CARE TEACHING METHODS

Billings and Block have delineated a series of evidence-based recommendations for teaching palliative care that are readily adaptable to the primary care setting.[1] These principles can be a pedagogical guide to the design of learning experiences in primary care.

Teaching in the primary care setting revolves around clinical experiences with patients as well as structured educational exercises (postclinic rounds, conferences, journal clubs, and seminars). When students and residents have the opportunity to care for patients they have known in the primary care setting who are terminally ill, special learning opportunities arise. Caring for a patient whom the student or resident has followed over time represents a "teachable moment" in medical training, when the learner is likely to be particularly receptive to teaching about palliative care because of the connection with the patient and the commitment to providing longitudinal care. Students and residents should be encouraged to follow such patients intensively in whatever setting the patient is receiving care. Involvement with hospice and home visiting should be encouraged.

Case-based discussion, role playing, standardized patient exercises, and lectures should be used to expose learners to the range of palliative care issues. Teaching should emphasize different types of death experiences to provide students with knowledge and perspective on different disease processes. Cases can emphasize both communication and management issues and give learners opportunities to practice clinical skills.

Faculty in the primary care setting should view both practical teaching about end-of-life patient management and attention to the learner's emotional responses to the clinical situation as their responsibility, and should closely supervise the learner's experience and attend to his or her emotional responses. Balint Group–type meetings, in which participants meet to talk about difficult cases and their emotional reactions to the work of doctoring, are an excellent venue for discussions of emotional responses to dying patients. Stories from literature and other forms of artistic expression also may be valuable as teaching tools, facilitating discussion of personal reactions to dying patients.

As part of primary care rotations, each student and resident should participate in collaborative, longitudinal hospice and nursing home experiences, including interdisciplinary team meetings, patient home visits, and telephone contact with patients, families, and hospice nurses. Learners should be exposed to a variety of dying experiences, directly or indirectly through discussions with other students and clinicians about their patients. Optimally, students should have an opportunity to participate in or witness a positive model of dying in which patient and family members have an opportunity for closure and reconciliation in the dying process.

Evaluating Clinical Competence in Palliative Care

Evaluation of palliative care competence in the primary care setting should parallel other evaluations of clinical competence and should be both formative and summative. Modified objective structured clinical examinations (OSCEs) should be designed to assess clinical skills, decision making, clinical reasoning, and ethical problem solving around end-of-life issues. Prescribing analgesics, breaking bad news, and assessment of depression in the terminally ill are important topics that would lend themselves to this approach. Standardized patients enacting common primary care end-of-life situations can also be useful in assessing and providing feedback to learners. Another underutilized modality of evaluation is feedback from patients and families. Although such evaluations may vary in quality, debriefing and discussion by the learner and a faculty mentor may be a valuable way for the learner to obtain formative feedback.

INSTITUTIONAL SUPPORT

Optimal integration of palliative care into primary care education requires institutional support from several sources.

Medical Schools and Teaching Hospitals

As primary care educational experiences are now integrated broadly across the entire spectrum of medical education, there are many opportunities to teach palliative care. Each medical school needs to develop a coherent plan outlining how palliative care will be taught in primary settings. An oversight body with responsibility for reviewing palliative care content across the entire curriculum would facilitate appropriate inclusion of this material in preclinical education and clinical teaching sites, and would reduce gaps and improve the efficiency of the educational program in palliative care.

Faculty Development

Few faculty have a solid foundation of knowledge about palliative care from their medical school or residency training. Yet, many of the traditional continuing medical education (CME) programs—grand rounds, primary care teaching conferences, and journal clubs—include little content related to palliative care. Primary care conference schedules should include regular presentations on various facets of palliative care, in which both fundamentals and new developments are presented. Primary care CME programs should include palliative care as a core content area.

Exemplar faculty development programs should be provided to help faculty acquire communication, mentoring, and other teaching skills related to end-of-life care. Successful courses on palliative care or end-of-life communication skills have been developed and conducted by the Project on Death in America Faculty Scholars Program, the Medical College of Wisconsin,[28] and the Harvard Medical School Division of Medical Ethics. These models (and others) can serve as blueprints for institutional initiatives in faculty development.

Finally, faculty teaching palliative care in the primary care setting will benefit from access to appropriate teaching resources that address these topics in the primary care setting. Videotapes, clinical cases, reading lists, syllabi, standardized patient scripts, OSCE designs, knowledge assessment instruments, and CD-ROM technologies relevant to this area should be collected, catalogued, and disseminated.

Improving the Research Base for Palliative Care

There are many basic research needs in palliative care as it relates to primary care. First, as noted by others, we need to know more about the epidemiology of dying.[9] Knowledge of where and how and under whose care patients die in the community and in the hospital will improve the match between physician education and the care needs of patients, and will inform planning for services. Little is known about the experience of primary care physicians providing palliative care to the dying. A better understanding about how care is shared by generalists and specialists, between hospices and primary care physicians, between community-based physicians and "hospitalists" will provide further understanding that can shape our training of students and residents. Data about the personal impact on physicians of caring for the dying are nearly absent from the literature. Such information has the potential to provide useful guidance to educators and clinicians about how to support primary care physicians in this function.

Development of Residency Program Guidelines

Residency review committees (RRCs), which establish guidelines for clinical training, play a determining role in graduate medical education. In general, RRCs have not mandated attention to palliative care issues in graduate training. However, the internal medicine RRC has recently revised its residency guidelines to include a requirement for instruction in palliative care and a recommendation for clinical experiences in hospice and home care. Changes in residency requirements in this area will require teaching hospitals to ensure that they have both faculty who are able to address the new training needs and appropriate clinical placements for residents.

Licensing and Certifying Examinations

The National Board of Medical Examiners and the internal medicine, pediatrics, and family medicine boards are including a growing number of questions related to palliative care on their examinations. As palliative medicine becomes better integrated into these examinations, medical school curriculum leaders are likely to increase the emphasis on this content in their curricula.

Role of National Primary Care Organizations

Major primary care organizations, as well as primary care educators' organizations (American Academy of Physician and Patient, Society of Teachers of Family Medicine) have an opportunity to assume leadership roles in improving education about end-of-life care. A consensus document developed by these organizations endorsing the importance of palliative care within primary care and suggesting implementation mechanisms for palliative care education would enhance the inclusion of this material in educational programs.

BARRIERS TO AND FACILITATORS OF CHANGE

An awareness of the barriers and incentives to change can provide leverage for the change process and help to foster integration of palliative care educational content across the educational spectrum. Leadership from primary care division or department chiefs, primary care clerkship directors, and residency training directors will be essential in implementing these recommendations. In addition, institutional commitment to integrating palliative medicine content throughout the medical school curriculum will further facilitate adoption of these proposals in the primary care setting.

A number of barriers to enhanced palliative care education in the primary care setting, however, are likely to remain. First, because palliative medicine is an emerging discipline, the lack of institutional palliative care programs or linkages with community hospice programs in many settings is likely to hinder the development of educational opportunities for students and residents in primary care. Further, lack of a vision of what excellence in end-of-life care can offer to the patient and family in the dying process may limit aspirations and expectations of both students and faculty, resulting in acceptance of suboptimal care processes and outcomes. A lack of adequately trained faculty to promote and implement this vision and these new educational offerings is another major barrier to change.

LIMITATIONS

The consensus recommendations presented here represent the opinions of a diverse and knowledgeable panel of experts. A major limitation to our process is the inadequacy of the research database about palliative care education. We do not have generalizable, well-evaluated models for educating medical students and residents about the care of the dying. Thus, our recommendations were based heavily on "expert opinion." Although we included some nonphysician experts in the process, educational models designed for other disciplines might have provided helpful input. Patient and family opinion was not represented in our deliberations. Finally, our group process did not use a full range of formal methods for arriving at consensus. We were fortunate that there was ready agreement among the participants about the key recommendations.

SUMMARY

The confluence of enhanced attention to primary care and palliative care education presents educators with an opportunity to improve both (as well as patient care) through integrated teaching. Improvements in palliative care education will have benefits for dying patients and their families, but will also extend to the care of many other primary care patients, including geriatric patients and those with chronic illnesses, who make up a large proportion of the adult primary care population. In addition, caring for the dying, and teaching others to carry out this task, can be an important vehicle for personal and professional growth and development for both students and their teachers.

Support for the National Consensus Conference on Medical Education was provided by the Project on Death in America of the Open Society Institute and by the Robert Wood Johnson Foundation (grant 029360).

Helpful editorial suggestions were provided by J. Andrew Billings, MD, and David Barnard, PhD.

REFERENCES

1. Billings JA, Block SD. Palliative care in undergraduate medical education: status report and future directions. JAMA. 1997;278:733–8.
2. Dickinson G. Changes in death education in U.S. medical schools during 1975–85. J Med Educ. 1985;60:942–3.
3. Merman AC, Gunn DB, Dickinson GE. Learning to care for the dying: a survey of medical schools and a model course. Acad Med. 1991;66:35–8.
4. Holleman WL, Holleman MC, Gershenhorn S. Death education curricula in U.S. medical schools. Teaching Learning Med. 1994;6:260–3.
5. Belani CP, Belcher AE, Sridhara R, Schimpff SC. Instruction in the techniques and concept of supportive care oncology. Support Care Cancer. 1994;2:50–5.
6. Kitchen AD. Potentials and pitfalls in death education in medical schools. In: DeBellis R, Marcus ER, Kutscher AH, Klagsbrun SC, Seeland IB, Preven DW, eds. Thanatology Curriculum—Medicine. New York, NY: Haworth Press; 1988:3–13.
7. Billings JA. Medical education for hospice care: a selected bibliography with annotations. Hospice J. 1993;9:69–83.
8. Preven DW. Where are we and where are we going? In: Schoenberg B, Carr AC, Kutscher AH, et al, eds. Education of the Medical Student in Thanatology. New York, NY: Arno Press; 1981:64–8.
9. Lattanzi ME. Learning and caring: education and training concerns. In: Corr CA, Corr DM, eds. Hospice Care: Principles and Practice. New York, NY: Springer Publishing; 1983:223–36.
10. Field MJ, Cassell CK. Approaching Death: Improving Care at the End of Life. Institute of Medicine Committee on Care at the End of Life. Washington, DC: National Academy Press; 1997.
11. Solomon MZ, O'Donnell L, Jennings B, et al. Decisions near the end of life: professional views on life-sustaining treatments. Am J Public Health. 1993;83:14–23.
12. Lomas J. Words without action? The production, dissemination, and impact of consensus recommendations. Annu Rev Public Health. 1991;12:41–65.
13. Fink A, Kosecoff J, Chassin M, Brook RH. Consensus methods: characteristics and guidelines for use. Am J Public Health. 1984;74:979–83.
14. Tresolini CP, and the Pew-Fetzer Task Force. Health Professions Education and Relationship-Centered Care. San Francisco, Calif: Pew Health Professions Commission; 1994.
15. Osterweis M, Solomon F, Green M. Bereavement: Reactions, Consequences, and Care. Washington, DC: National Academy Press; 1984.
16. McWhinney IR, Stewart MA. Home care of dying patients: family physicians' experience with a palliative care support team. Can Fam Physician. 1994;40:240–6.
17. Von Gunten CF, Von Roenn JH, Neely KJ, Martinez J, Weitzman S. Hospice and palliative care: attitudes and practices of the physician faculty of an academic hospital. Am J Hosp Palliat Care. 1995;12:38–42.
18. Steinmetz D, Walsh M, Gabel LL, Williams PT. Family physicians involvement with dying patients and their families. Arch Fam Med. 1993;2:753–60.
19. Schneiderman LJ. The family physician and end-of-life care. J Fam Pract. 1997;45:259–62.
20. MacDonald N, Mount B, Boston W, Scott JF. The Canadian palliative care undergraduate curriculum. J Cancer Educ. 1993;8:197–201.
21. Hafferty FW, Franks R. The hidden curriculum, ethics teaching, and the structure of medical education. Acad Med. 1994;69:861–71.
22. Bowlby J. Attachment and Loss, Volume I, Attachment. New York, NY: Basic Books; 1969.
23. Bowlby J. Attachment and Loss, Volume II, Separation: Anxiety and Anger. New York, NY: Basic Books; 1969.
24. Bowlby J. Attachment and Loss, Volume III, Loss, Sadness and Depression. New York, NY: Basic Books; 1969.
25. Freud S. Mourning and melancholia. In: Freud S. Collected Papers, Volume 4. New York, NY: Basic Books; 1959:152–170.
26. Lindemann E. Symptomatology and management of acute grief. Am J Psychiatry. 1944;101:141–8.
27. Forrow L, Arnold RM, Parker LS. Preventive ethics: expanding the horizon of clinical ethics. J Clin Ethics. 1993;4:287–94.
28. Weissman DE. A faculty development course for end-of-life care. J Palliat Med. 1998;1:35–44.