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Few U.S. Public Health Schools Offer Courses on Palliative and End-of-Life Care Policy

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Abstract

Background: Palliative care has been identified by the World Health Organization (WHO) as a critical policy element for the relief of suffering, yet palliative care policy receives minimal attention in mainstream U.S. public health journals, conferences, or textbooks. In the '90s, documentation of the lack of attention to end-of-life and palliative care in medical and nursing curricula led to concerted efforts to improve medical and nursing education in palliative care. No such educational effort has yet been directed toward public health professionals.

Objective: This study's objective was to quantify current course offerings covering palliative and end-of-life care from a public health and health policy perspective at accredited schools of public health.

Design: Using a list of keywords about palliative and end-of-life care, the research team searched publicly accessible websites of all CEPH accredited and affiliated U.S. schools of public health to identify courses that included relevant content about palliative care.

Results: For academic years 2011/12 and 2012/13, 3 (6%) of the 49 accredited U.S. schools of public health offered a full course covering public health issues in palliative care. Six schools (12%) included some palliative care content in related courses such as gerontology policy.

Conclusions: Schools of public health are not preparing future policy experts with a basic knowledge of the components and systems of palliative care and hospice. Development and dissemination of appropriate curricular material to address the public health and policy aspects of palliative care is needed to address this gap.

Introduction

THE WORLD HEALTH ORGANIZATION (WHO) considers palliative care an essential and effective part of a comprehensive cancer control policy.¹ The 58th World Health Assembly resolution on cancer prevention and control (WHA 58.22), adopted in May 2005, describes palliative care as one of the four pillars of cancer control and calls on WHO Member States to implement cancer control programs that include palliative care.² More than a decade ago, WHO noted that, "Many countries have not yet considered palliative care as a public health problem and, therefore, do not include it in their health agenda."³ Despite calls from WHO and from palliative care leaders for the inclusion of palliative care on the public health agenda,⁴⁻⁷ palliative care is seldom addressed in mainstream U.S. public health journals, conferences, or textbooks. In the United States, it is only after many years of conspicuous absence that the most recent public health plan, Healthy People 2020, includes a brief mention of palliative care as an emerging issue, calling for

"Increasing and measuring access to safe long-term and palliative care services and access to quality emergency care."⁸

Several European countries are farther advanced than the United States in applying a population-based, public health approach to palliative care. In England, the work of Murtagh and colleagues refined methods for population-based estimates of palliative care need,⁹ leading to new initiatives and funding models proposed by policymakers.¹⁰ Recently German researchers developed the first targets for public health initiatives to improve palliative care in Germany,¹¹ and the European Association for Palliative Care has laid out a comprehensive palliative care agenda.¹² Despite progress in other developing and developed countries, the United States has largely left palliative care off of the public health agenda. With the notable exception of Rao's work in 2005 to develop an end-of-life agenda for state health departments¹³ and MedPAC's continuing scrutiny of access and cost of the Medicare Hospice Benefit,¹⁴ there is scant public health literature addressing palliative care in the United States.

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A public health approach to palliative care involves applying the population-based view that is the essence of public health to a health problem, service-delivery issue, or health policy challenge.¹⁵ It entails using the tools of public health (such as epidemiology, health services research, and policy analysis) to characterize and solve a health issue. This contrasts with the clinical tools and clinical skills that are applied by individual clinicians (or teams) to individual patients during the delivery of care. In the United States a great deal of effort has focused on educating clinicians to deliver palliative care and on researching effective clinical interventions. Indeed, the progress in the clinical area and in clinical education is heartening.¹⁶ But serious system-level issues, such as the need to update the payment model for the Medicare Hospice Benefit, cannot be solved through clinical research or intervention. Only a public health approach will provide the needed information and analysis to improve care at the system level.

Into the foreseeable future, the United States is certain to continue to face systemwide challenges in providing high-quality, cost-effective, person-centered care of the seriously ill. Preparing the next generation of public health practitioners to meet this challenge through the application of public health's population-based tools seems to the authors to be an obvious priority for public health education. Outside of one elective course, attention to palliative care issues was notably absent from the literature and issues to which the authors were exposed as public health students. The authors were concerned that this almost complete silence about a public health and public policy approach to palliative care might also be true of the curriculum in other U.S. schools of public health. If public health schools are not educating new public health practitioners about palliative care policy issues, this silence will likely be perpetuated by the next generation of public health practitioners, making it difficult for the United States to make progress in systemic improvements in palliative care.

Previous studies on palliative care curricula

Although numerous studies of medical and nursing school palliative care curricula have been conducted, there are no prior published studies on the integration of palliative care into the public health curriculum. Studies of medical education documented an initial alarming gap—and then substantial improvements—over the past 20 years.^{17,19,21} These and other studies were summarized in a comprehensive chapter on medical education deficiencies in the influential 1997 Institute of Medicine (IOM) Report, *Approaching Death: Improving Care at the End of Life*, which concluded that medical education at the time was woefully deficient with regard to dying patients, the “end stages of diseases,” and palliative care.²²

This IOM report also summarized deficiencies in nursing education.¹² The IOM called for major improvements in physician, nursing, and social work education, and this call led to major national initiatives such as the Education in Palliative and End-of-life Care (EPEC) program for physicians²³ and the End-of-life Nursing Education Consortium (ELNEC) program for nurses.²⁴

The current study was conducted in order to determine whether a similar gap existed in public health education. Based on the senior author's experience in developing a full

course on palliative care health policy issues for a school of public health, we expected to find sparse attention paid to palliative care in public health school curriculums. We hoped that documenting such a gap, if it existed, could lay the groundwork for more attention to this critical topic in public health education.

Methods

Web survey of public health courses

A survey of web-posted palliative care curricula among public health schools accredited by the Council on Education for Public Health was conducted in April and May 2012. Students pursuing master's degrees and enrolled in a Hospice and Palliative Care Policy course at the George Washington University School of Public Health and Health Services designed and carried out a two-step survey process. In the first step of the research, each student in the class was assigned five or six schools to research. Students searched school websites for publicly accessible information on the palliative and hospice care courses offered in the 2010–2011, 2011–2012, and 2012–2013 school years as part of curricula for master's degrees in public health (MPH). Students were instructed to act as though they were a prospective MPH student with an interest in palliative care trying to determine whether courses meeting their interest were available. A list of suggested keywords was developed to guide the search:

- advance directives
- advanced directives
- advanced illness
- bereavement
- chronic disease
- chronic illness
- death
- dying
- end of life
- hospice
- palliative
- serious illness
- terminal

Students were permitted to vary the search parameters in response to what they found on each school's website, as prospective students of such programs might do. Courses had to be listed as school of public health courses. Courses at the same university that might have been available to public health students (such as courses offered at related schools of medicine or nursing) were only counted if they were also listed in the school of public health catalogue.

Students entered the information into a shared data collection spreadsheet. The same process was repeated in a second data collection wave, with different students assigned to each school, in order to independently verify the information gathered in the first round. The 2010–2011 school year was subsequently removed from further study, because many of the school websites did not provide public access to older course listings.

Evaluation of curriculum

The data collection spreadsheets were combined into one master spreadsheet with all personal information on the

student researcher removed. Courses were included in the analysis even if only found in one of the two research rounds. Four of the authors independently categorized all of the courses into one of five pre-defined categories. The senior author then reviewed all ratings to resolve discrepancies and determine a final category rating. During this review, the senior author reduced the original five categories to three: (1) a full course on palliative care issues from a public health/health policy perspective offered in the school of public health, (2) a public health course on a related topic (often gerontology) with some coverage of palliative care, or (3) a full course on palliative issues from a clinical or management point of view.

Results

During the 2011–2012 and 2012–2013 academic school years, there were 49 CEPH accredited schools of public health and 6 associate schools in the United States and its territories. As seen in Table 1, of these schools, only three (George Washington University, Johns Hopkins University, and University of Minnesota) offer full courses dedicated to palliative and hospice care from a public health or health policy approach. Each school offered one course. Thus, only 6.1% (3/49) of accredited and 5.6% (3/55) of all schools of public health offered courses dedicated to palliative health and hospice issues.

In the less-restrictive second category, six schools (10.9% of accredited and associate schools) offered a total of 10 courses indicating in the course descriptions that palliative and hospice care issues would be addressed in the context of other public health issues such as aging, ethics, and HIV/AIDS. These courses often put palliative and hospice issues in the context of another public health discipline such as management, epidemiology, or community health. Schools offering these courses were Georgia Southern University, Johns Hopkins, Loma Linda, University of Michigan, and UNC Chapel Hill.

Lastly, courses concentrating on palliative and hospice care from a clinical or management perspective are sometimes open to public health students through related medicine and nursing schools. We identified five schools each offering one such course cross-listed in public health (Emory, Harvard, Johns Hopkins, University of Louisville, and University of Maryland.)

Discussion

Our Internet search identified only three public health schools that offered full courses on the public health or health policy approach to palliative and end-of-life care issues in the 2011–2012 and 2012–2013 academic years. The existence of three such courses demonstrates that there is sufficient content to create a full course on the public health perspective of palliative and end-of-life care, yet few schools have done so to date. Below are the topics covered and objectives of the one-credit, six-session course offered at George Washington University in 2011 and 2012.

Course objectives

- Attain thorough familiarity with history and current structure of delivery of hospice and palliative care services.
- Be able to use Dartmouth Atlas data to assess medical care used by Medicare patients in the last years and months of life.
- Know the major information sources on utilization of hospice and palliative care.
- Know the main quality measurement projects for hospice and palliative care and the way that they are being integrated into new payment structures such as ACOs.
- Gain understanding of current policy issues about hospice and palliative care, including access to appropriate care, structuring funding to avoid waste, measuring and reporting quality, and advanced directives.
- Practice analyzing policy issues using appropriate evidence and applying useful analytic approaches. Focus will be on two current policy issues: (1) whether Medicaid programs should opt out of providing hospice benefits and (2) topic of students choice related to public health “blind spot” about end of life.
- Articulate a public health framework for palliative care.
- Understand global perspective on promoting palliative care.
- Participate in researching and writing a paper for publication.
- Appreciate the emotional, artistic, and existential reactions often experienced when contemplating death, dying and bereavement and understand that these may influence rational policy making.

TABLE 1. ACCREDITED OR ASSOCIATE SCHOOLS OF PUBLIC HEALTH OFFERING COURSES WITH SUBSTANTIAL PALLIATIVE CARE CONTENT IN 2011/2012 AND 2012/2013 ACADEMIC YEARS

	<i>Schools listing one course per year</i>	<i>Schools listing two or more courses per year</i>	<i>Total number of schools/total number of courses</i>
Full course on palliative care issues from a public health/health policy perspective	3	0	3 schools/3 courses
Related topic in public health and health policy including some course content on palliative care and hospice	3	3	6 schools/10 courses
Clinical or management courses with some palliative care or hospice content; listed in school of public health catalogue	5	0	5 schools/5 courses

Course outline

Session #1:

- Epidemiology of dying in the U.S.
- Cultural attitudes towards dying and death
- History of hospice and PC, including the SUPPORT Study, its assumptions, impact
- Definition and description of hospice care
- Definition and description of palliative care

Session #2:

- The landscape of end-of-life care: Dartmouth Atlas data
- Regulatory and financing mechanisms for hospice and palliative care

Session #3:

- A “Good Death”—measuring and improving the quality of end-of-life care
- Medicaid and Hospice

Session #4:

- Advocacy before policymakers—role play of advocating for the Florida Medicaid Hospice Benefit
- Workforce preparation and education

Session #5: Global perspectives on palliative care

Session #6: Student selected topic presentations

Students at the 94% of schools without a full course may get some exposure in other courses in related areas, such as gerontology or long-term care management, but that exposure appears to be quite minimal. Although we found many courses in related areas, such as geriatric health policy, we could not always locate or access more detailed information about the content of the course. If none of the searched key words appeared in the course description, we assumed that the course contained negligible coverage of the topics.

Where we were able to review course content, we found that actual content devoted to palliative care or end-of-life issues, at least as documented in curriculum documents available to us, was quite modest. For instance, a course at Loma Linda University School of Public Health entitled, “HIV/AIDS: Implications for Public Health” mentions that students may do their fieldwork at a hospice site. A course on long-term care administration entitled “Seminar in Issues of Long-Term Care Administration and Policy” at the University of Michigan addresses hospice through a case study in 1 class out of a total of 13. The syllabus also mentions that advance directives may be discussed. Similarly, a course entitled “Aging and Public Policy” at the University of North Carolina at Chapel Hill Gillings School of Global Public Health includes one class on advance directives and euthanasia under the class title “Should People Have the Choice to End Their Lives? Advance Directives, Euthanasia, Hospice service.”

Two gerontology courses at Johns Hopkins School of Public Health mention end-of-life issues in their course descriptions, but in such a way that one expects that the issues are approached mainly from a clinical standpoint (the delivery of services to individuals) rather than from a broad population health standpoint. In the first course description, death and dying is categorized in the “clinical” category and is not mentioned in the “broad social and policy implications” or “financial implications” categories. In the second course de-

scription, terminal illness is listed as one of many “threats to health and independence in later years,” with the implication that there are scientific advances that can possibly remove or ameliorate this threat. Language to suggest that public health concerns and approaches such as equitable access to services, sustainable funding models, or evaluation of delivery models might be applied to the area of palliative and end-of-life care is notably absent from these and other course descriptions and material that was reviewed.

Highly motivated students might be able to pursue further study of palliative and end-of-life care by taking related courses at associated medical and nursing schools. We found a number of courses offered by schools of medicine, nursing, and an ethics institute, but these tended to be clinical in focus, rather than policy focused. Clinically focused courses on communication, grief and bereavement, and concerns of the dying patient were offered at many schools of nursing and medicine, but these were not cross-listed in the catalogues of the school of public health nor did they seem to have a public health approach. Furthermore, the policies on whether students have to pay extra tuition for these courses or can get credit toward graduation vary greatly across schools. We did not judge availability of clinical courses at sister medical and nursing schools an adequate answer to having this area covered by appropriate courses within the school of public health itself.

We are aware of at least one comprehensive course on palliative care health policy issues offered outside of an accredited school of public health. The National Institutes of Health offers graduate and undergraduate courses through the Foundation for Advanced Education in the Sciences (FAES) (www.faes.org/grad). In the spring of 2012, the FAES offered a 12-week course on public policy issues in palliative care entitled, “End-of-Life and Palliative Care in Public Health: Strategies, Systems and Challenges for Health Services,” as part of its public health certificate (catalogue course listing: faes.org/sites/faes.org/files/resources/faes201213.pdf).

A clear limitation of our method was that we were limited to reviewing the course descriptions and materials that were posted in public areas of school websites. Examination of materials such as more detailed course descriptions, syllabi, or reading lists available to enrolled students may have revealed that some of these courses included more content about palliative and end-of-life issues. However, these materials are often posted in controlled areas of the website where access is granted only to students enrolled in those courses, putting them beyond the scope of our inquiry.

In our introduction, we asserted that the U.S. public health community has paid scant attention to palliative care issues. This article documents that gap specifically in the course offerings of schools of public health. Future research should aim to quantify the gaps in other avenues of dissemination of public health research and thought, namely journal articles, conference offerings, and research funding. Quantifying and characterizing those gaps is a first and necessary step toward rectifying them.

Conclusion

Given that such a large part of our health care resources are devoted to care of people toward the end of life and that

hospice and palliative care have demonstrated their capacity to alleviate so much avoidable suffering, it is imperative that students of public health come away from their education with a basic knowledge of the components, systems, and policy challenges of palliative care and hospice. There are several additional steps schools of public health can take to make palliative and end-of-life care a standalone topic of interest. Using the course outline and objectives provided in this article, schools and their faculty can offer a hospice and palliative care policy course of their own. However, we are aware that not all schools will have the desire or resources to establish an entire course. In that event, there are other options available, including short lecture series, guest lecturers in related courses, seminars, and promoting local opportunities and conventions offered by national organizations.

We presume that the existing lack of attention to hospice and palliative care in health policy and public health curricula stems in part from lack of expertise on the part of public health school faculty. This suggests that an effort should be made to develop a model curriculum with a “train the trainer” approach that would make it feasible for existing faculty to inject more palliative care material into their courses, and possibly to offer full courses covering palliative care issues.

Students can also take it upon themselves to educate their peers and sponsor activities. By utilizing student organizations and advocating to faculty and school officials, students can begin a grassroots effort. On the individual level, students can publish research on this topic, can participate in research forums, or can write their culminating degree thesis on hospice and palliative health policy. Student organizations can sponsor guest lectures, awareness days, and discussion groups to spread the word and advocate for this important but often overlooked piece of health policy.

Beginning in February 2013, the IOM²⁵ is revisiting its landmark 1997 report that sparked a welcome sea change in clinical education in palliative care skills. We urge the IOM to note the gap that still exists in the education of public health practitioners and to call for attention to palliative care in the public health curriculum. Now that these critical gaps in the public health curriculum have been identified, we urge that they be speedily addressed through the development, testing, and promulgation of curricular material specific to the public health and policy issues needed to ensure high quality, accessible, and efficient palliative and end-of-life care.

Author Disclosure Statement

The authors have no conflicts of interest to disclose.

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