The Supply, Demand and Use of Palliative Care Physicians In the United States

A Report Prepared for the Bureau of HIV/AIDS, Health Resources and Services Administration

September 2002

Center for Health Workforce Studies
School of Public Health
University at Albany, Room B-334
1 University Place
Rensselaer, NY 12144
518-402-0250   Fax: 518-402-0252
http://chws.albany.edu

Preface

Increasing concern regarding the care and support services available to patients diagnosed with terminal illnesses or chronically disabling conditions has stimulated debate on the feasibility of expanding palliative care services in hospital, hospice and community settings. Among the key issues to be sorted through is the role that physicians will play in designing, delivering and/or coordinating such services for patients and their families. Understanding current physician practice patterns, as well as opportunities in the field, is important to determine the workforce strategies best able to promote delivery of more effective palliative care in the United States.

With grant support from the Bureau of HIV/AIDS, Health Resources and Services Administration (HRSA) and extensive assistance from the Center to Advance Palliative Care (CAPC) at the Mount Sinai School of Medicine, the New York Center for Health Workforce Studies (CHWS) was able to examine the supply, demand and use of palliative care physicians in the United States.

CHWS appreciates the interest and invaluable support provided to this research effort by Diane Meier, M.D., Robert D'Antuono and Michael Joiner at CAPC, including assistance in identifying key informants and willingness to reflect with staff on policy questions critical to our understanding of this emerging field. The American Board of Hospice and Palliative Medicine, the American Academy of Hospice and Palliative Medicine and the National Organization of Hospice and Palliative Care generously shared their membership lists and encouraged physician participation in the study. CHWS also appreciates the support of the Montefiore Hospital. Many physicians and representatives of health care organizations shared time and insights with us. In particular, we would like to express our appreciation to George Davis, M.D. and Molly Poleto, R.N. whose interest and perspectives assisted us throughout the project.

CHWS is a not for profit research center operating under the auspices of the University at Albany of the State University of New York and Health Research Incorporated (HRI). CHWS is dedicated to the collection and analysis of health workforce data to assist providers, educators, policy makers and the public better understand issues related to the health workforce.

Bonnie Primus Cohen, MS., Associate Director of CHWS, and Edward Salsberg, MPA., Director of the CHWS prepared the report. Other CHWS staff contributing to the study include Mark Beaulieu, Gaetano J. Forte, Debra Krohl, Yoshiko Yamada and Shiratapa Mohapatra. Ideas expressed in this report are those of the authors and do not represent the views of the School of Public Health, State University of New York; HRI; CAPC; or HRSA.

Table of Contents

Tables and Figures

Executive Summary

Palliative care is interdisciplinary care focused on the relief of suffering and the improvement of quality of life. It can be combined with efforts to cure and control disease or it may be the total focus of care. As the number of older people in the United States increases and as advances in medical interventions prolong life for many affected by illnesses previously regarded as terminal, the availability of trained health care professionals skilled in palliative care becomes crucial.

The "Study on the Supply, Demand and Use of Palliative Care Physicians in the United States" was undertaken to help determine workforce strategies that would promote more effective palliative care in America. The Bureau of HIV/AIDS of the U.S. Health Resources and Services Administration funded the Center for Health Workforce Studies at the University of Albany, SUNY and the Center to Advance Palliative Care at the Mount Sinai School of Medicine to complete a comprehensive study of the palliative care physician workforce.

The Center for Health Workforce Studies (CHWS) is a research center of the School of Public Health at the University of Albany. CHWS seeks to increase access and to improve the quality, efficiency and equity of healthcare by encouraging training, distribution and use of health personnel consistent with health needs. CHWS collects, analyzes and shares information to help direct public and private policies related to the use of health workers. The Center to Advance Palliative Care (CAPC) is a national initiative of the Robert Wood Johnson Foundation with technical assistance provided by the Mount Sinai School of Medicine. CAPC was established to promote wider access to excellent palliative care in hospitals and health systems nationwide through the development of new, high quality delivery programs and model practices.

Methodology

To reach the overarching goal of identifying effective workforce strategies that promote effective palliative care, the research project was designed to:

- Assess the current supply and demand for physicians with palliative care expertise;
- Identify current practice patterns by physicians with palliative care expertise;
- Assess the use of such services by individuals with HIV/AIDS and other chronic illnesses; and
- Assess options for expanding the supply of physicians with palliative care expertise including establishing a formal subspecialty recognized by the American Board of Medical Specialties (ABMS).

Several activities were undertaken to gather data and perspectives on the supply, demand and use of physicians. These include:

- DEVELOPMENT AND ANALYSIS OF TWO NATIONAL PALLIATIVE CARE SURVEYS. One survey was directed to palliative care physicians and a second was directed to hospitals providing formal palliative care services.

  1. Palliative Care Physician Survey.

  Surveys were distributed to 2423 physicians who are certified by the American Board of Hospice and Palliative Medicine (ABHPM), the American Academy of Hospice and Palliative Medicine (AAHPM) and/or who are Medical Directors of hospices that are members of the National Hospice and Palliative Care Organization (NHPCO). These are key professional organizations addressing issues related to palliative care and the physician workforce. Physicians affiliated with these organizations were thought to address issues related to palliative care, including death and dying, more frequently than physicians in general.

  The response rate to the physicians survey was 52%, with 1271 physicians responding. Respondents reflect the geographic distribution of physicians associated with ABHPM, AAHPM and NHPCO. The response rate to the survey by ABHPM certified physicians was 65.4%. ABHPM is a national medical board that oversees the voluntary certification of physicians and the development of standards for training and practice in palliative medicine. Since ABHPM certification is voluntary, these respondents are likely to represent the physicians with greatest interest, commitment and knowledge in the field. ABHPM physicians constitute 39% of all respondents.

  2. Hospital Survey.

  Surveys were distributed to 572 hospitals that provide or plan to provide formal palliative care programs. These hospitals were identified through a previous national survey conducted by CAPC and the American Hospital Association as organizations that provide formal palliative care programs or planned to develop such programs. Of the hospitals sent CHWS surveys, 64% responded. Respondents are representative of the geographic distribution of all the hospitals CHWS surveyed.

- INTERVIEWS. Face to face and telephone interviews were conducted with experts in the field of palliative care; medical school educators affiliated with allopathic and osteopathic schools of medicine; and physician leaders from medical specialties that frequently care for patients with chronically disabling or terminal illnesses.
- LITERATURE REVIEW. A review of literature on palliative care was conducted, with particular focus on physician workforce issues. Subject areas addressed and summarized include: (1) Improving Care for People with Serious and Life Threatening Illness: An Overview; (2) Emerging Palliative Care Programs in Hospitals; (3) Education and Training for Physicians in Palliative Medicine; (4) Determining the Desirability of New Medical Specialties; (5) Barriers to the Provision of Palliative Care; and (6) Challenges in Delivering Palliative Care Services to Patients with HIV/AIDS.

Detailed descriptions of the results of each component are described in Chapter 2.

Findings of the Study

The "Study of the Supply, Demand and Use of Palliative Care Physicians" yielded a picture of palliative care physician workforce and identified challenges and barriers confronted in the delivery of palliative care. Findings are presented within the following categories: (1) The Palliative Care Physician Workforce; (2) Training and Education of Palliative Care Physicians; (3) A Profile of Hospitals Providing or Planning to Provide Formal Palliative Care Programs; (4) Development of a Formal Medical Subspecialty in Palliative Medicine; (5) Patients Receiving Palliative Care Services; (6) Key Non-Physician Personnel Providing Palliative Care; (7) Assessment of the Marketplace for Palliative Care Physicians; and (8) The Role of Public Education in Influencing the Delivery of Palliative Care Services. A comprehensive presentation of study findings can be found in Chapter 3. Key findings follow:

(1) The Palliative Care Physician Workforce

- Two distinct groups of physicians providing palliative care on a regular and focused basis emerged among the physicians surveyed: 1) a small group of physicians whose practices revolve significantly around the provision of palliative care, and 2). physicians involved on a modest, part time basis
- Physicians committing 20+ hours weekly to palliative care constitute 25.9% of the population surveyed, but provide almost 70% of the total hours devoted to palliative care activities that were reported. Physicians working 9 or fewer hours weekly in the practice of palliative care constitute 53.2% of palliative care physicians surveyed, and provide 14% of the services.
- Thirty nine per cent of the physician respondents are members of the American Board of Hospice and Palliative Medicine (ABHPM) The palliative care practices and perspectives of this group of physicians differ from the non certified physicians.
- The majority of physicians not currently working 100% in palliative care would prefer to provide more palliative care.

(2) Training and Education of Physicians

- There is general agreement that all physicians should have background and skills enabling them to provide quality care to patients with serious and life threatening medical conditions. Improving the quality of training and education on palliative care for ALL PHYSICIANS is the workforce strategy most frequently identified by physician and hospital respondents to promote more effective palliative care in the United States in the long term.
- A core body of knowledge is recognized to exist in palliative medicine.
- While 70.5% of physicians certified by ABHPM felt their training in palliative medicine adequately prepared them for palliative care practice, only 37.9% of non certified physicians felt adequately prepared. Physicians working 20+ hours weekly in palliative care were more likely to feel their training in palliative medicine adequately prepared

them (54.9%) than physicians working fewer hours. Respondents working 9 or fewer hours in the field were least likely to feel their training prepared them for palliative care practice (34.5%).

(3) A Profile of Hospitals Providing or Planning to Provide Palliative Care Services

- Hospitals anticipate changes in their formal palliative care services including increases in the number of patients served (76.2%), expansion of the type of services offered (66.8%) and/or redesign of services (48.4%) over the next 18 months.
- Close to 70% of the hospital respondents report that at least one physician working in their formal palliative care programs is ABHPM certified. Most hospitals report a small number of physicians working in their formal palliative care programs.
- Hospitals prefer recruiting physicians with backgrounds in Internal Medicine, Pain Management, Oncology/Hematology, Geriatrics and Family Practice when recruiting for their palliative care programs. Completion of EPEC courses, ABHPM certification and completion of palliative care fellowship programs are the education and training backgrounds required or preferred in candidates.

(4) Development of a Formal Medical Subspecialty in Palliative Medicine

- The majority of palliative care physician respondents and hospital respondents favor the development of a formal American Board of Medical Specialties (ABMS) subspecialty in palliative medicine.

(5) Patients Receiving Palliative Care Services

- Cancer is the most common diagnosis of patients who receive palliative care services as reported by physician respondents (91.7%) and hospital respondents (88%). COPD is the second most common diagnosis reported by physicians (54.4%) and hospitals (56.2%). CHF is the third most common diagnosis reported by the physicians (53.6%) and hospitals (56.2%). Patients diagnosed with these three diseases receive the majority of palliative care services currently provided within physician practices and formal hospital palliative care programs.
- Few patients diagnosed with HIV/AIDS receive care within physicians' palliative care practices or formal palliative care hospital programs.

(6) Key Non-Physician Personnel Providing Palliative Care

- RNs, social workers and chaplains are the non-physician personnel who work most routinely with physicians within their palliative care practices, and who work most frequently as part of core teams of personnel providing services in formal hospital palliative care programs.

(7) Assessment of the Marketplace for Palliative Care Physicians

- Physicians expect that their palliative care practices will grow.
- A majority of hospitals (53.7%) perceive the supply of physicians with training in palliative care to be insufficient to meet the available jobs in their communities over the next 3 years.
- Over half of ALL respondents do not regard the supply of palliative care physicians to be sufficient to meet the needs of patients and families for services.
- Physicians generally perceive current opportunity in palliative care as limited. Physicians making broader commitments to the field in training and time are more likely to report current opportunities in palliative care in their communities.
- Expanding and improving financing for palliative care services are regarded by physicians and by hospitals as key to delivering this care.

(8) The Role of Public Education in Influencing the Delivery of Palliative Care Services

- Public education is seen by hospital and physician respondents, medical educators and leaders from medical specialties that frequently care for patients with serious chronic and life threatening illness as a means to promote increased demand for palliative care and, in so doing, to influence physician, hospital and other provider practices.

Discussion of Findings

Study findings suggest that the workforce strategies needed to support the delivery of improved palliative care will be broad in scope. The discussion that follows highlights issues that will impact the direction of future palliative care physician practice and services. A full discussion of findings is presented in Chapter 4.

Physician Workforce

Physicians included in the study are affiliated with professional organizations promoting palliative care, and are thought to address issues related to such care, including death and dying, more frequently than physicians in general. Significant differences among current palliative physicians were found to exist in terms of their patterns of practice. These differences include but are not limited to the amount of practice time committed to palliative care, the perceptions held regarding sufficiency of services to meet patient and family need, and the roles assumed within the field. Physicians working 20 or more hours weekly in palliative care practice constitute 25% of the physicians responding to the CHWS survey, while providing 70% of all services reported. Physicians working 9 or fewer hours per week in palliative care constitute 53% of the respondents and provide 14% of the services reported. Physicians spending 20 or more hours weekly in palliative care practice are the most likely to perceive need for palliative care services by patients and families, which may be a consequence of their time commitment in this area. They also are more likely to teach, conduct research, provide direct patient care, and consult to other physicians and health professionals than colleagues committing fewer hours to the field each week.

Training and Education

There is general agreement that a core body of knowledge in palliative medicine exists and that the palliative care approach should be incorporated into training provided to new and to mid career physicians. Improving training for all physicians in palliative care was the workforce strategy physicians and hospital respondents cited most frequently to improve the quality of palliative care in the U.S. While efforts are underway to build palliative care into medical school curricula and professional association programs, palliative care issues are not yet fully integrated within educational offerings.

Since physicians are seen to make different commitments to palliative care within their practices, future training for physicians will not be uniform but tiered in design: programs will be needed to provide understanding and skill development appropriate for those physicians who only occasionally address the death of patients; for those working on a modest, part time basis and likely to serve a limited program population; and for those concentrating their medical practice in this area and who work in one or more worksites and/or programs.

Current palliative care physicians have relied on a range of educational and training programs to prepare them for practice in the field. These include short courses, fellowship programs, residency rotations and medical electives. EPEC offerings can be seen to play a very important role in providing core information to physicians. ABHPM has provided an additional opportunity for palliative care physicians to gain and to demonstrate expertise in the field through voluntary board certification in palliative medicine.

While the majority of physicians surveyed completed some type of formal training, one fifth of palliative care physicians completed no formal training in palliative medicine. Establishing professional performance standards within different care settings is one strategy to assure that doctors have skills and expertise consistent with best practices within the field.

Hospitals Providing or Planning to Provide Palliative Care Services

Efforts to formalize hospital based palliative care services have increased in the past two decades in order to improve the quality of services available to patients and families. While the design and array of services offered vary, it appears that hospitals offering formal palliative care programs remain very committed to them. Survey findings suggest that formal services are most frequently found in larger hospitals and in nongovernmental not for profit hospitals. It appears that there are extensive opportunities for the introduction of such services in other hospitals across the country.

Most hospital services focus on meeting the needs of patients who are dying. The opportunity to demonstrate how palliative care services benefit patients with chronic care needs, in addition to end of life needs, will also affect the design of services that hospitals ultimately introduce to respond to needs in their communities and is likely to increase demand.

Patients Accessing Palliative Care Services

Disparities exist among patients diagnosed with terminal illnesses regarding access to palliative care services. Formal services are most likely to be provided to patients with a small number of diagnoses. These diagnoses include Cancer, Chronic Obstructive Pulmonary Diseases (COPD), and Congestive Heart Failure (CHF). While patient access to these services reflects physicians' current understanding of the progression of these illnesses and their consequent ability to predict a time frame for death, it also reflects regulatory practices that tie reimbursement for palliative care services to life expectancy, e.g. the Medicare Hospice benefit. To the extent that palliative care comes to be understood as including services provided over the duration of a life threatening illness and also appropriate for the treatment of care for serious and chronic conditions, the range of diagnoses commonly treated will expand.

Physician discomfort with confronting the death of patients and /or breaking bad news to patients and family members further impacts the options communicated to patients with life threatening illnesses. Influencing practice patterns of physicians is an important strategy to assure that all patients and families are permitted timely consideration of curative and palliative approaches to treatment.

Income, citizenship and geography further influence which patients will be able to consider accessing existing palliative care services. Some population groups face particular challenges in accessing palliative care services, including minorities, women, individuals with histories of chemical dependencies, immigrants and children.

Patients Diagnosed With HIV/AIDS

Few patients diagnosed with HIV/AIDS receive care within physicians' palliative care practices or within formal palliative care hospital programs. Less than 5% of the physician respondents report HIV/AIDS as a common diagnosis in their practices, while 40% have no patients with this diagnosis in their practices. Similarly, one in ten of the hospital respondents commonly have HIV/AIDS patients in their programs while close to half have no HIV/AIDS patients in formal palliative care programs. HIV/AIDS patients may be receiving palliative care from other physicians, hospital programs, or other service systems, but they are not utilizing the formal services studied in significant numbers.

HIV/AIDS is now regarded as a highly treatable disease. Many HIV/AIDS patients experience difficulty accessing healthcare generally. This presents particular challenges in the delivery of end of life care. HIV/AIDS patients are reported to be more under-treated for pain than cancer patients. Those HIV/AIDS patients with histories of substance abuse may be further discriminated against in receiving pain medication due to concerns regarding past or present dependencies. Many HIV/AIDS patients may have added problems in communicating with physicians due to histories of poverty, ethnic and cultural backgrounds, or because they are children. Assuring that doctors and/or teams of health professionals treating these patients have demonstrated skills in facilitating communication and in establishing trust and understanding of unique individual needs is particularly needed to address the needs of people with this illness.

The Marketplace for Physicians Providing Palliative Care

There are mixed findings in assessing the marketplace for physicians providing palliative care. Almost 80% of all physician respondents perceive that their palliative care practices will grow in the next 3 years. Those physicians with ABHPM certification and working 20 + hours in palliative care were more likely to expect significant growth. Hospitals project increases in services that will require their recruiting additional physicians credentialed in the field. Study findings suggest that the existing need for physicians and palliative care services by patients and families exceeds the availability of physicians to deliver services.

That said, physicians and hospitals respondents view current reimbursement levels and funding as inadequate to sustain physicians in practice and to fund the educational initiatives essential to assure that physicians are well trained in palliative medicine. Today only one tenth of the physician respondents derive their full income from palliative care. Hospitals report that predictable and adequate funding is essential to seed and operate programs. A *national approach to funding palliative care services was thought by many to be required to assure access to affordable medication and care provided by physicians and other health professionals across the continuum of health care settings.* Reimbursement is a means to incentivize desired changes in health delivery systems, but is currently experienced as a restraint in the area of palliative medicine.

Debate on the Desirability of an American Board of Medical Specialties (ABMS) Subspecialty in Palliative Medicine

The survey findings demonstrate that there is significant support for a formal medical subspecialty in palliative medicine from U.S. physicians currently affiliated with professional associations that address hospice and palliative medicine issues and from hospitals providing and or planning to provide formal palliative care programs. Physician support is greatest among doctors who already demonstrate strong commitment to the field by becoming voluntarily certified through ABHPM and /or by committing 20 or more hours to palliative care practice each week.

The ABMS subspecialty these physicians envision is not a substitute for the care provided by physicians already connected with patients. The need to assure coordination and continuity of care is voiced strongly in interviews and comments from survey respondents. Distinct roles for the palliative care physician are identified in the surveys including educator, consultant, researcher as well as provider of direct care. A small subspecialty would be able to fill these roles.

It is notable that physicians opposing a subspecialty object to the formalization of the field, not palliative care.

The Value of Educating the Public on Palliative Care

While there is consensus within the field that public education is a key strategy to improve the availability and delivery of palliative care, there are significant differences regarding what this care could include. Some in the field regard palliative services as end of life care. Some think it synonymous with hospice care. Others believe that palliative care includes a range of services that should be considered simultaneous to curative treatment and discussed as options with patients at the time of diagnosis of a serious illness. And still others believe palliative care includes comprehensive care that should be available to individuals affected by serious illnesses. Mixed messages within the field regarding the definition of services will impact the ability of advocates to educate the public as well as influence public and private reimbursement practices developed to respond to public demands for palliative care.

While physicians responding to the study's survey believed that public education is key to improving care, few allocate time for this among their weekly activities.

The Palliative Care Team

The palliative care approach is distinguished by the involvement of a team of individuals able to respond to the range of physical, emotional, spiritual and support service needs of patients and their families. Registered nurses, social workers and chaplains are key professionals working with physicians and in hospital programs to deliver palliative care services. Examining the outcomes achieved through different team approaches will benefit planning for implementation of new programs. It will also inform development of training that promotes skill development for team members specific to their fields or specific to work within palliative care teams. Further, documentation of effective team strategies can influence the design of future reimbursement practices.

Recommendations to Improve the Delivery of Palliative Care

The goal of the palliative care physician study was to identify workforce strategies that promote the delivery of more effective palliative care in the United States. Strategies and a comprehensive listing of recommendations to achieve this goal are presented in Chapter 5. The proposed strategies and key recommendations follow:

<u>Strategy I: Improve education and training in palliative medicine for all physicians serving patients with chronic and life threatening illnesses.</u>

Recommendations:

- Provide physicians with increased opportunities for clinical experiences in palliative care and exposure to physician role models during medical school training.
- Increase information sharing among medical schools on approaches taken to integrate palliative medicine into undergraduate, clerkship and residency programs.
- Survey physicians in specialties that frequently treat patients with chronic and terminal illness on the need for, access to and use of emerging palliative care programs.
- Convene a strategic planning forum to identify strategies to increase mid career physician understanding and skills in palliative medicine.
- Expand the availability and sponsorship of EPEC programs so that mid career physicians in specialties that frequently care for patients with chronically disabling and terminal illnesses consider attending.

Strategy II: Establish an ABMS subspecialty in palliative medicine.

Recommendation:

- Palliative care professional associations should pursue the development of a small medical subspecialty in palliative medicine certified through ABMS.

Strategy III. Clarify the roles that palliative care physicians play in different health care settings.

Recommendations:

- Examine and compare the roles played by palliative care physicians in settings including hospices, hospitals, nursing homes and academic institutions.

Strategy IV. Expand financing for palliative care services.

Recommendations:

- Reimbursement policies should encourage investment of health care resources in programs that increase the quality of life for patients with chronic illness and/or near the end of life. Sustained and adequate funding streams should support the development and operation of formal palliative care programs in hospitals and other settings and should encourage professionals to work in this field.
- Study the impact of current reimbursement policies on the time committed to and role played by physicians providing palliative care services in different health care settings.
- Adapt state and federal policies to promote coordination of care across settings.
- Medicare, Medicaid and private payer reimbursement policies should reinforce delivery of high quality, cost effective care and that reflect best practices within the field of palliative medicine. Eligibility criteria for the Medicare Hospice benefit should be *widely clarified* by the Center for Medicare and Medical Services.

Strategy V: Understand the supply, demand and use of non-physician health care professionals with training in palliative care.

Recommendations:

- Study the current supply, demand and use of nurses, social workers and clergy who are delivering palliative care services.
- Examine the role and needs of caregivers in the delivery of services.
- Promote palliative care training for new and midcareer nurses, social workers, clergy and pharmacists.

Strategy VI. Assure that palliative care services are available to individuals diagnosed with HIV/ AIDS.

Recommendations:

- Physicians working with HIV/AIDS patients should be required to demonstrate understanding and skill in palliative care including the ability to discuss the end of life concerns with patients.
- Communication training to facilitate timely discussion of treatment options including end of life issues should be required for physicians treating HIV/AIDS patients.
- Explore ways to assure that the resources of palliative care programs are available to HIV/AIDS patients, either through consulting or direct service.
- Under treatment of pain is reported to be significant for HIV/AIDS patients, with women, children and past or current injection drug users as particularly vulnerable. Promoting dialogue among treating physicians and palliative care physicians may support development of protocols and treatment for HIV/AIDS patients.

Strategy VII: Increase public understanding of palliative medicine and end of life issues.

Recommendations:

- Encourage educational programs that stimulate debate on palliative care at national, state, and local levels.
- Physicians should be encouraged to increase time committed to pubic education to stimulate discussion of palliative care in their communities.

Strategy VIII: Identify strategies to embed palliative care into physician practices throughout health care delivery systems.

Recommendations:

- Document strategies that have proved effective in influencing physician behavior around palliative care issues within or across medical systems in order to facilitate incorporation of palliative care principles in caring for patients with serious, chronic and life threatening illnesses more broadly.
- Promote quality initiatives that assure access to palliative care programs across healthcare settings.
- Conduct research that examines factors that determine patient eligibility to participate in palliative care programs.
- Document the impact of formal palliative care programs on care provided in health care settings.
- Fund palliative care research/ centers.

Chapter 1: Introduction

Palliative care is not focused on cure, but on relief of suffering and improvement in quality of life from early through late stages of illness. As the number of older people in the United States increases, outpacing the rate of growth of the population as a whole, and as advances in medical interventions prolong life for many affected by illnesses previously regarded as short term and fatal, the availability of trained healthcare professionals to care for people with chronically disabling and /or terminal illnesses becomes crucial. Care will be needed to meet the physical, spiritual, emotional and support service needs of patients and their families.

Since World War II, health care investment has favored scientific, curative interventions at the expense of a focus on reducing suffering for those nearing the end-of-life. This bias has been reflected in education and training provided to health care professionals, including physicians. Growing recognition of the deficiencies in our current health care systems in serving people coping with death and dying has resulted in activity on several fronts: Formal palliative programs have been established, first through the hospice movement and more recently through the development of hospital based palliative care programs. Philanthropists and foundations have helped to seed these programs and to stimulate professional training for health care professionals. Academic and clinical educational programs are being reexamined, spurred in part by public policy and standard setting initiatives addressing death and dying. Increased media coverage informing the public about options for care of serious illness has further stimulated understanding and debate regarding the care we can expect as we or loved ones approach the end of life. And further, increasing numbers of practitioners are raising concerns regarding care. Many are joining professional organizations promoting palliative care and/or seeking additional skill training, demonstrating their own interest and commitment to the field.

This activity is notable. So too are the remaining challenges. These include adapting our national health care policies and health care systems to assure patient centered care; influencing physician practice patterns; assuring sustained funding sources for palliative services; and assuring access to services by patients.

Project Goals

The “Study of the Supply, Demand and Use of Palliative Care Physicians in the United States” was undertaken to help determine workforce strategies that would promote more effective palliative care in America. The Bureau of HIV/AIDS at the U.S. Health Resources & Services Administration funded the Center for Health Workforce Studies at the University of Albany, SUNY and the Center to Advance Palliative Care at the Mount Sinai School of Medicine to complete a comprehensive study of the palliative care physician workforce. The Bureau of HIV/AIDS was also interested in determining the availability of palliative care physicians to treat individuals with HIV/AIDS. Understanding the role that physicians play in designing, coordinating and delivering these services was recognized as a key element in influencing health care available for patients as they deal with serious illness or approach death.

To reach the overarching goal of helping determine workforce strategies to promote more effective palliative care in the U.S., the research project was designed to:

- Assess the current supply and demand of physicians with palliative care expertise;
- Identify current practice patterns of physicians with palliative care expertise;
- Assess the use of palliative care services by individuals with HIV/AIDS and other chronic illnesses; and
- Assess options for expanding the supply of physicians with palliative care expertise, including establishing a formal American Board of Medical Specialties subspecialty.

Definition of Palliative Care

Palliative care is comprehensive, interdisciplinary care for patients whose disease is chronic and progressive, or unresponsive to curative treatment. It includes pain and symptom management as well as psychological, emotional and spiritual care. The goal of palliative care is to achieve the best quality of life for patients and their families, regardless of life expectancy.

Palliative care services include a broad range of patient care, family support, bereavement and community support services. Services are provided in a variety of settings: inpatient and outpatient hospital settings, hospices, nursing homes and at home.

There has been considerable debate regarding the definition of palliative care. For some it is inextricable with good patient care. It is not an alternative to curative interventions, but thought to be complementary to them. For advocates of this perspective, the course of a disease would determine the approach to care that would be emphasized. Many see it as appropriate to introduce the subject of palliative care options when patients are first diagnosed with chronic or terminal illness. In contrast, others view palliative care as the appropriate approach only when curative care is no longer viable and/or when death is imminent. For them palliative care is synonymous with end of life care. Services covered by third party payers may further restrict common understanding or usage of the term by tying eligibility for palliative services to projected time of death or by limiting the health care personnel authorized to provide care.

As indicated above, palliative care has been understood to be comprehensive care for the purposes of this study. It is not limited to care at the very end of life, nor to treatment of terminal illnesses. Palliative care is an approach that may involve interventions over the progression of a disease, and would be appropriate for treatment targeted to patients with long term disabling conditions. This broader definition was used in considering the issues addressed by the study, including examination of the advisability of developing a medical subspecialty in palliative medicine. It is understandable that the definition of palliative care is in flux as this is an emerging area in medicine. The definition ultimately embraced will be significant in shaping the course of the field.

Chapter 2 –Summary Descriptions of Results of Research Activities

The Center for Health Workforce Studies (CHWS) conducted a series of activities to gather data and perspectives on the supply, demand and use of physicians providing palliative care services in the United States. These activities included: (1) the development and analysis of two national surveys, one directed to palliative care physicians and one directed to hospitals that provide or plan to provide formal palliative care programs; (2) face to face and telephone interviews with experts in the field of palliative care, medical school educators and physician leaders in specialties that frequently care for patients with chronically disabling or terminal illnessses; and (3) a review of the literature on palliative care. Descriptions and results of these activities follow.

A. Survey of Physicians Providing Palliative Care Services in 2001

1. Background

In fall, 2001, the Center mailed surveys to 2423 physicians identified with the practice of palliative care across the United States. The survey was designed to clarify physicians' current practice patterns and to increase understanding of the supply and demand for physicians with this background. Information was sought to provide a demographic profile of palliative care physicians; elicit their assessment of the adequacy of past training in palliative care; identify roles and activities performed routinely in providing palliative care; and clarify assessments of opportunities for future work in this area. The study further sought to gauge support for the development of an American Board of Medical Specialties subspecialty in Palliative Medicine, and to better understand the provision of palliative care services to people diagnosed with HIV/AIDS and other chronic diseases.

The American Board of Hospice and Palliative Medicine (ABHPM) and the American Academy of Hospice and Palliative Medicine (AAHPM) shared their mailing lists with CHWS for this effort, and the National Hospice and Palliative Care Organization (NHPCO) provided its list of hospice medical directors. These organizations also cosigned a letter of support endorsing the study and encouraging participation by all physicians (Appendix A). Packets sent in the mailing to the physicians included a letter from CHWS describing the project, the joint letter of support, a four page survey (Appendix B), a form indicating willingness to participate in future palliative care physician studies and a return envelope. The mailing lists provided were merged so that physicians would receive only one initial packet of material. Two additional survey mailings were conducted at three-week intervals to reach physicians who did not return the original material.

Professional Affiliations of Palliative Care Physicians

Figure 1 presents the affiliations of respondents to the survey. As some physicians are associated with more than one group, duplicate affiliations were accounted for in the analyses.

Figure 1. Professional Affiliations of Palliative Care Physicians

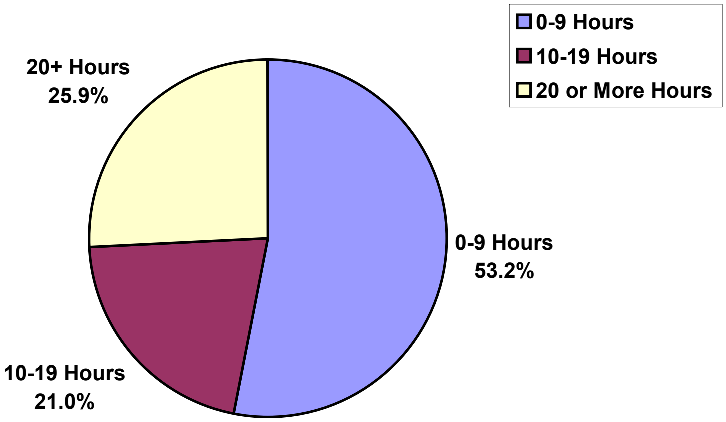
Percent of Respondents	ABHPM	AAHPM	NHPCO
28.9%			X
23.8%		X	
16.4%	X	X	
11.3%	X		
8.4%	X	X	X
8.3%		X	X
2.9%	X		X
Total	39.0%	46.9%	48.5%

The response rate to the physician survey was 52.5% with a total of 1271 physicians responding. The response rate for physicians certified by ABHPM was 65.4%. Since ABHPM certification is voluntary, these respondents are likely to represent physicians with greatest interest, commitment and knowledge in this field. Board v. non board affiliation was identified as a key variable in interpreting survey results. ABHPM certified physicians constitute 39% of all respondents.

Practice Hours Committed to Palliative Care

An initial review of the physician survey responses indicated that a second significant factor distinguishing among palliative care physicians was “hours per week devoted to palliative care”. Physicians were asked how many hours they worked each week in palliative care. Their activities could include clinical and non- clinical tasks and responsibilities, e.g. direct care, administration, research and teaching. Figure 2 illustrates that respondents fell into one of three groups: Approximately one fourth of the respondents devoted 20 or more hours to palliative care activities weekly. Approximately one fifth devoted between 10 and 19 hours to palliative care weekly. Over half worked nine or fewer hours in this area within their weekly practice. Sixty per cent of this third group devoted four or fewer hours per week to palliative care.

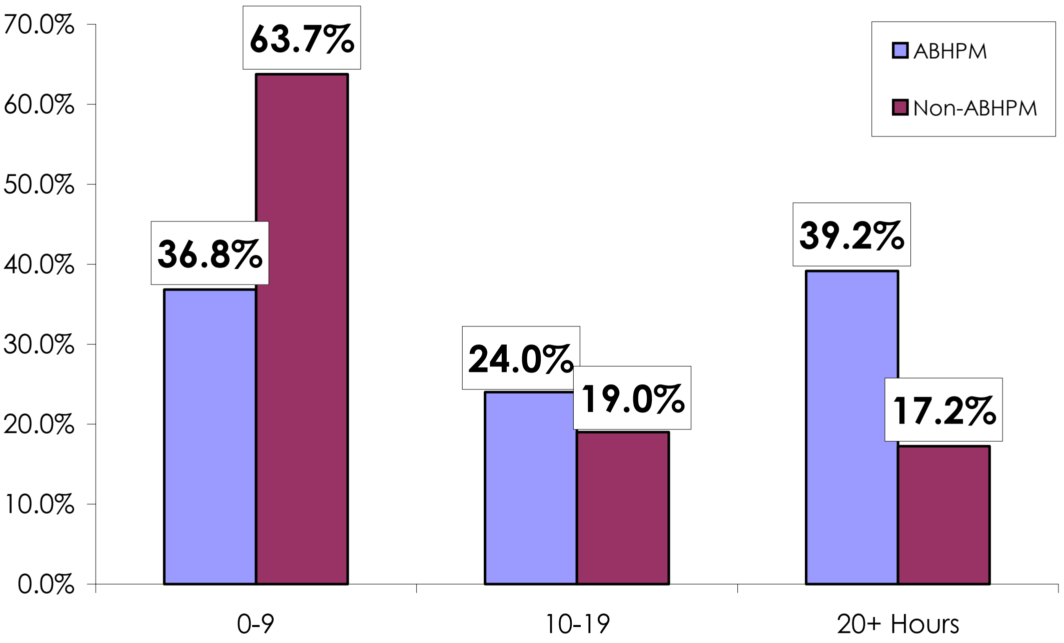
Figure 2. Hours Per Week Devoted by Respondents to Palliative Care Practice



The physicians working 20 or more hours each week (25.9% of the palliative care physicians) accounted for 68.7% of the total hours committed to palliative care by all respondents. The physicians working 9 or fewer hours (53.2% of the palliative care physicians) accounted for 14% of the total hours committed to palliative care.

Three fifths of the physicians working 20 or more hours each week are ABHPM certified. Almost three quarters of the physicians working 9 or fewer hours are non-ABHPM certified.

Figure 3. Weekly Commitment of Time by ABHPM and Non-ABHPM Survey Respondents



Approximately 13% of respondents reported having fulltime practices in palliative care. Of those physicians spending less than 100% of their practice in palliative care, 62.5% (620 physicians) reported that they would prefer to increase their time in this area. Over three quarters of the ABHPM certified physicians reported this preference (77%) and over half of the non-ABHPM certified physicians (55.9%) reported this preference.

2. Demographic Profile of Palliative Care Physicians

Physician respondents are primarily male (76.9%), and, as a group, they mirror the national distribution of physicians by gender (78.3% male, 21.7% female). The percentage of women respondents among ABHPM certified physicians (27.9%) is greater than among non ABHPM certified respondents (20%), and greater among physicians working 20 hours or more weekly in palliative care practice (28.2%) than physicians working 0- 9 hours weekly in palliative care (19.8%).

Figure 4. Palliative Care Physicians: Percent Female.

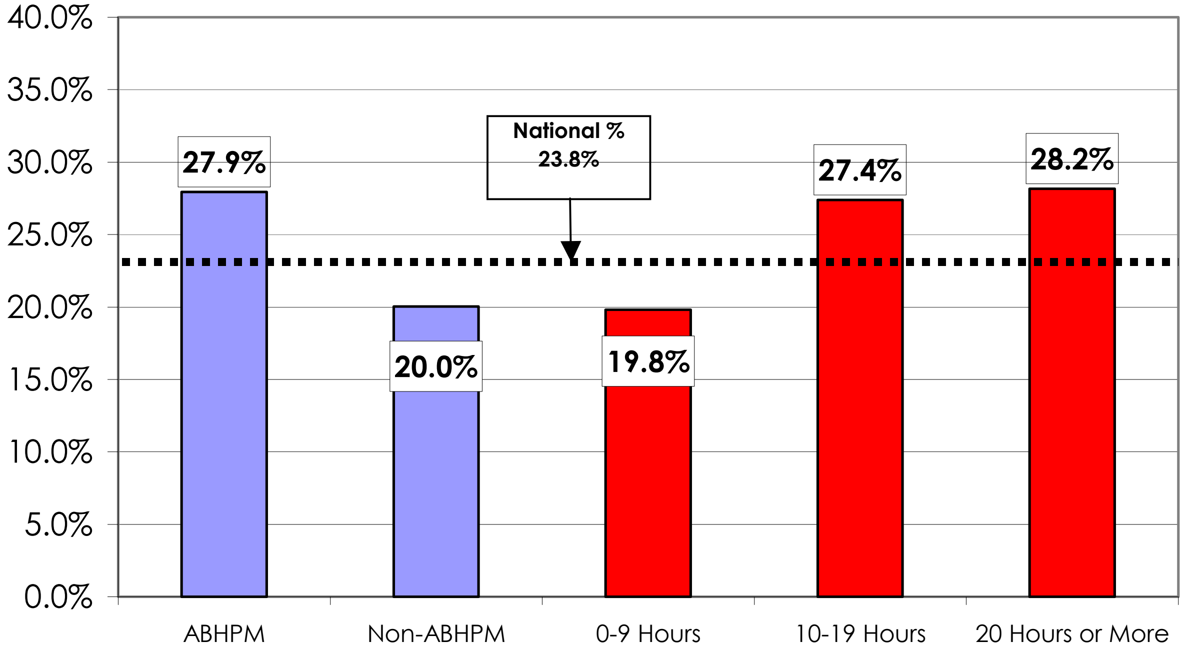
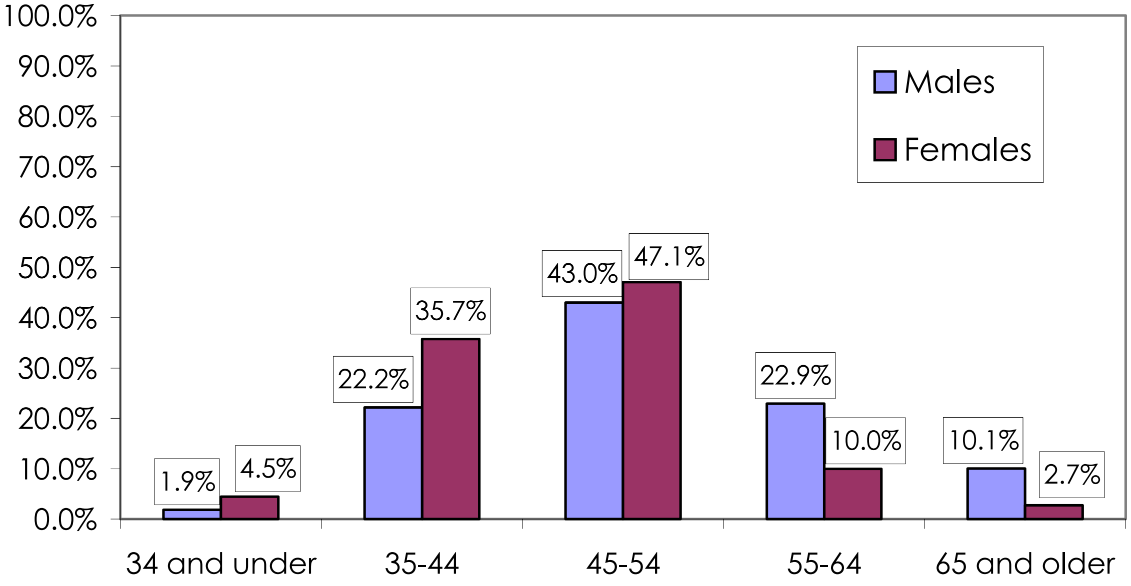


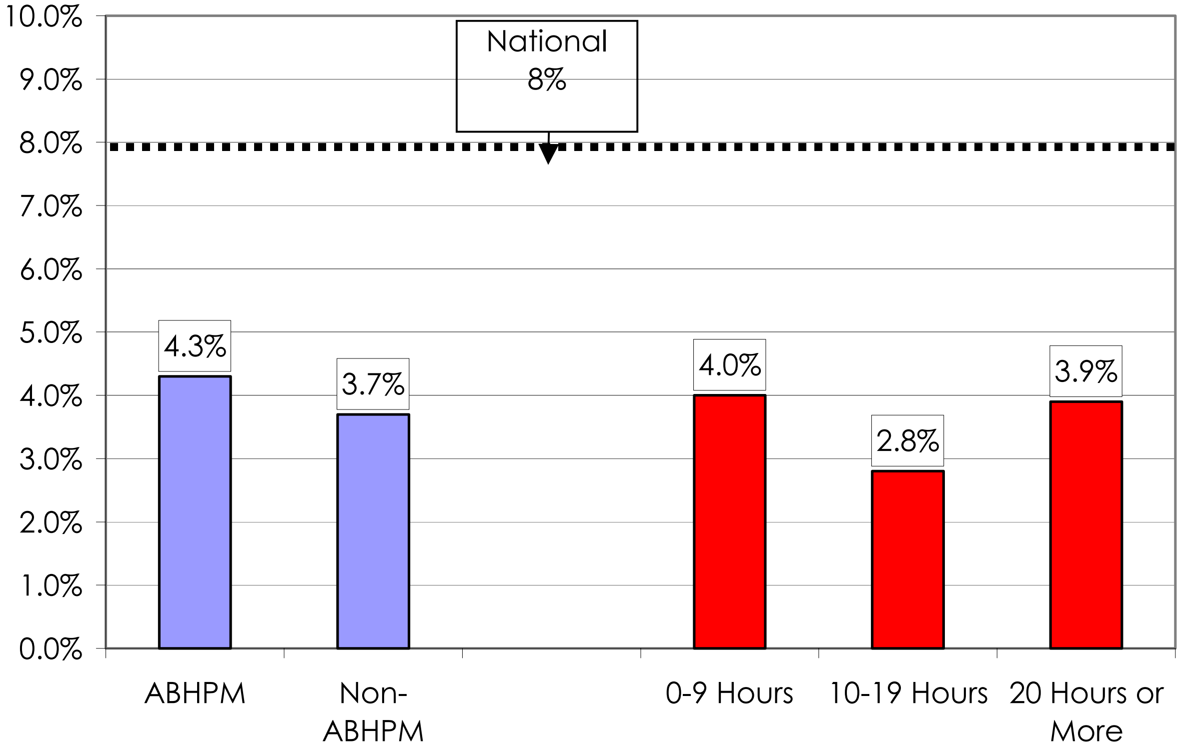
Figure 5 illustrates the distribution of survey respondents by age and gender. The majority of palliative care physicians are in their middle years, with 43.7% ages 45-54 as compared with the national average of 30.9% for this age category. Palliative care physicians are less likely to be 34 years or under than physicians nationally.

Figure 5. Distribution of Palliative Care Physicians by Age and Gender.



Survey respondents are primarily white. Black/African Americans, Hispanic/Latinos, and Native Americans are *more underrepresented* among palliative care physicians than they are among physicians as a whole. Asians and Pacific Islander respondents represent 4.8% of all survey respondents, while they represent 13.1% of all physicians nationally.

Figure 6. Palliative Care Physicians: Percent of Underrepresented Minorities.



The distribution of palliative care physicians across the country is consistent with the distribution of physicians nationally. The distribution of ABHPM physician respondents to non ABHPM physician respondents is also consistent nationally, with the exception of the West North Central region where there are 5.5% more non ABHPM physicians than ABHPM physicians. The distribution of respondents to the survey is illustrated in Figure 7. The distribution of ABHPM physicians sent surveys is illustrated in Figure 8.

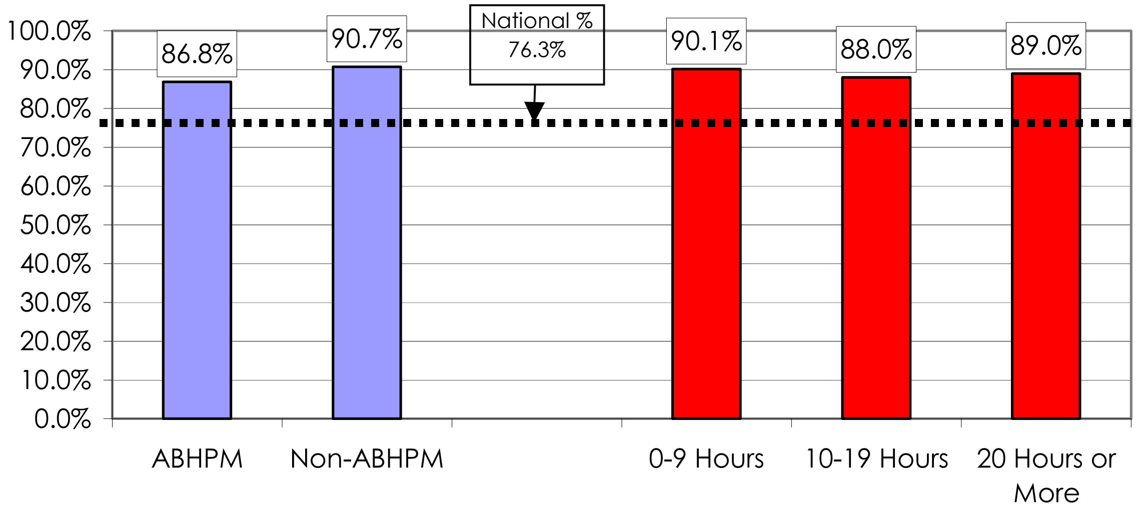
Figure 7. Distribution of All Physicians Responding to CHWS Palliative Care Survey

Figure 8. Distribution of ABHPM Physicians Sent the CHWS Palliative Care Survey.

3. Medical Education and Palliative Care Training

Palliative care physicians are more likely to be graduates of United States medical schools (89.2%) than U.S. physicians generally (76.3%). Graduates of osteopathic medical schools are represented in slightly larger numbers among palliative care physicians than their numbers nationally (7.6% to 5.3%).

Figure 9. Palliative Care Physicians: Percent U.S. Medical School Graduates



The medical specialties from which most physician respondents are drawn include Internal Medicine (42.2%), and Family Practice (31.3%)[1]. The medical subspecialties most reported by the respondents are Oncology/Hematology (20.7%), Geriatrics (16.5%) and Pain Management (7.8%). ABHPM certified physicians and physicians working 20+ hours in the field weekly are most likely to have backgrounds in Internal Medicine. Non-ABHPM certified physicians and physicians working 9 or fewer hours in the field are most likely to have backgrounds in Family Practice.

Table 1. Specialties and Subspecialties of Physicians Providing Palliative Care Services

Specialties of Respondents	ABHPM	Non-ABHPM	0-9 Hours	10-19 Hours	20 Hours or More
Internal Medicine	56.7%	32.9%	36.4%	46.4%	50.3%
Family Practice	25.9%	34.7%	42.1%	23.2%	16.0%
Medical Oncology/Hematology	23.3%	19.0%	16.4%	29.2%	22.4%
Geriatrics	22.2%	12.8%	16.4%	19.2%	14.4%
Pain Management	13.1%	4.5%	3.8%	11.6%	13.5%

---

[1] Specialties reflect the number of physicians reporting background in an area. Physicians may indicate backgrounds in more than one area, e.g. Internal Medicine and Geriatrics.

The formal palliative care training programs physicians have participated in are identified in the tables that follow. Respondents may indicate more than one type of training.

Table 2. Formal Palliative Care Training Completed: Board and Non-Board

	ABHPM	Non-ABHPM
Education for Physicians on End of Life Care Course (EPEC)	42.3%	28.9%
EPEC Train the Trainer Course	31.7%	12.0%
Fellowship in Palliative Care	4.4%	2.3%
Medical School Elective	3.4%	4.4%
Residency Rotation	6.7%	7.6%
Short Courses	53.8%	47.4%
Other	25.2%	14.3%
None	14.1%	26.3%
Total	**496**	**775**

Table 3. Palliative Care Training Programs Completed By Gender: Board and Non-Board

	ABHPM		Non-ABHPM	
	Male	Female	Male	Female
Education for Physicians on End of Life Care Course (EPEC)	42.1%	42.0%	27.2%	36.6%
EPEC Train the Trainer Course	29.2%	38.4%	11.0%	16.3%
Fellowship in Palliative Care	3.9%	5.8%	2.1%	3.3%
Medical School Elective	2.8%	5.1%	4.1%	5.9%
Residency Rotation	6.5%	7.2%	7.0%	10.5%
Short Courses	54.5%	52.2%	48.3%	43.8%
Other	23.9%	29.0%	12.3%	22.2%
None	15.7%	10.1%	28.0%	20.3%
Total	**356**	**138**	**611**	**153**

Table 4. Formal Palliative Care Training Completed: Hours Worked Per Week

	0-9 Hours	10-19 Hours	20 Hours or More
Education for Physicians on End of Life Care Course (EPEC)	25.3%	36.4%	51.6%
EPEC Train the Trainer Course	12.8%	15.8%	37.5%
Fellowship in Palliative Care	0.8%	2.8%	8.7%
Medical School Elective	3.4%	6.7%	3.2%
Residency Rotation	6.6%	7.9%	8.3%
Short Courses	48.8%	54.5%	48.4%
Other	15.0%	21.3%	24.0%
None	27.3%	18.2%	13.5%
Total	**641**	**253**	**312**

Half of all survey respondents reported that their formal training in palliative care included participation in short courses. Almost 35% completed the Education for Physicians on End of Life Care (EPEC) course and almost 20% completed the EPEC Train the Trainer course, suggesting that these offerings have been a significant resource to physicians. ABHPM certified physicians were more likely to complete the EPEC programs than non ABHPM certified physicians. Female physicians who are ABHPM members were as likely as male ABHPM certified physicians to complete EPEC courses; female non ABHPM physicians were more likely to complete these programs than male, non ABHPM certified physicians. Female physicians in both groups were more likely to complete EPEC trainer training than male physicians.

Physicians working 20 or more hours weekly in palliative care were also far more likely to complete short courses and EPEC programs than physicians working 9 or fewer hours in palliative care. They also were more likely to participate in fellowship programs, suggesting that the fellowships are preparing physicians who will make broader commitments of time to palliative care practice.

Over 20% of the respondents across age groups have no formal training in palliative care. While this remains true for non ABHPM certified physicians across age groups, ABHPM certified physicians 64 or under were much more likely to have completed some palliative care education and training.

ABHPM certified physicians and physicians working 20 or more hour each week in this field were more likely to report that their palliative care training adequately prepared them for practice. ABHPM certified physicians across the five specialties/subspecialties from which most respondents were drawn reported being significantly more prepared than non ABHPM certified respondents in their respective fields.

Figure 10. Percent of Physicians Reporting Palliative Care Adequately Prepared Them for Practice

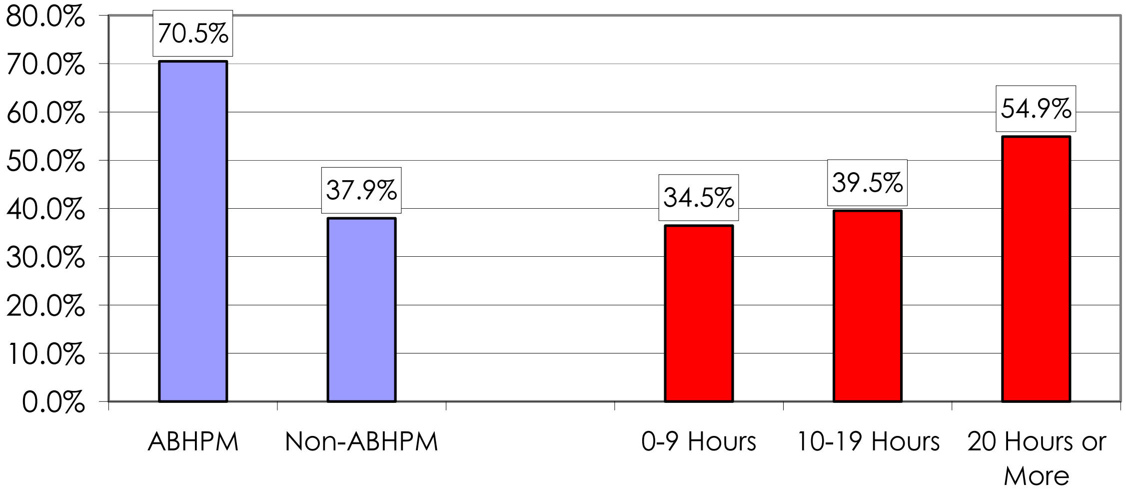
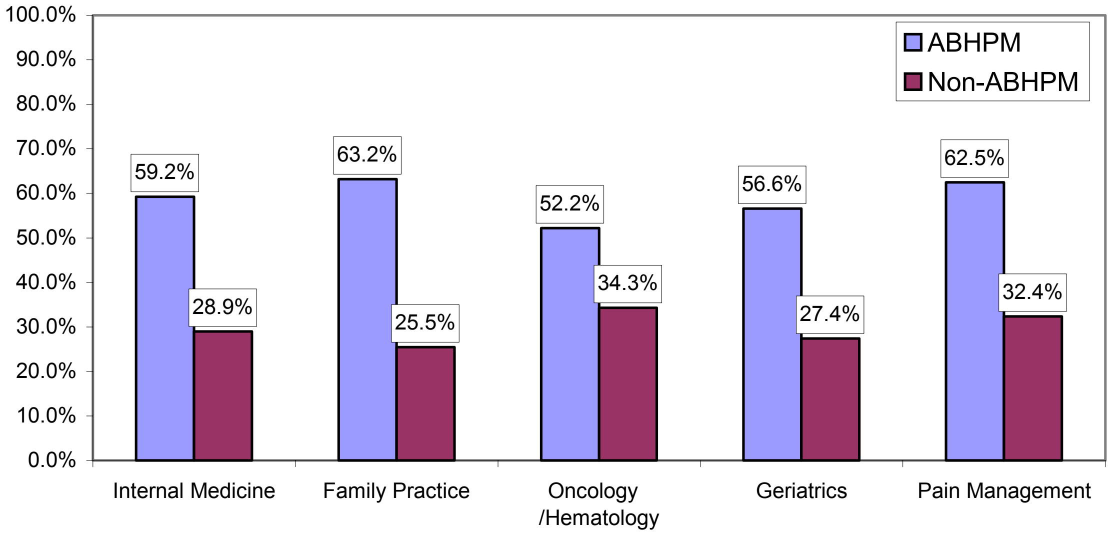


Figure 11. Adequacy of Palliative Care Training by Specialty



4. Medical Practice

Physicians were asked to identify the roles that they perform within their palliative care practice. The most frequent roles reported include: Medical director of a hospice (75.6%), direct patient care (71.7%), consultant to other health professionals (56%) and coordinator of palliative care team (52.8%). Tables 5 and 6 describe roles physicians perform.

Tables 5. Roles and Activities of Physicians Providing Palliative Care: Board and Non-Board

The Roles Performed in Palliative Care Within Current Practice	ABHPM	Non-ABHPM
Medical Director of hospice	69.3%	79.6%
Direct Patient Care	79.7%	66.4%
Consultant to other health professionals	60.6%	52.9%
Coordinate palliative care team	61.3%	47.2%
Administrative	45.3%	36.0%
Consultant to other MDs	51.5%	31.4%
Attend policy and clinical committees	44.5%	35.2%
Teaching	50.4%	21.6%
Medical Director of Palliative care service	35.2%	17.2%
Conduct home visits	33.2%	17.4%
Public education	16.5%	9.5%
Other	12.9%	6.9%
Research	10.3%	4.8%

Tables 6. Roles and Activities of Physicians Providing Palliative Care: Hours Worked Per Week

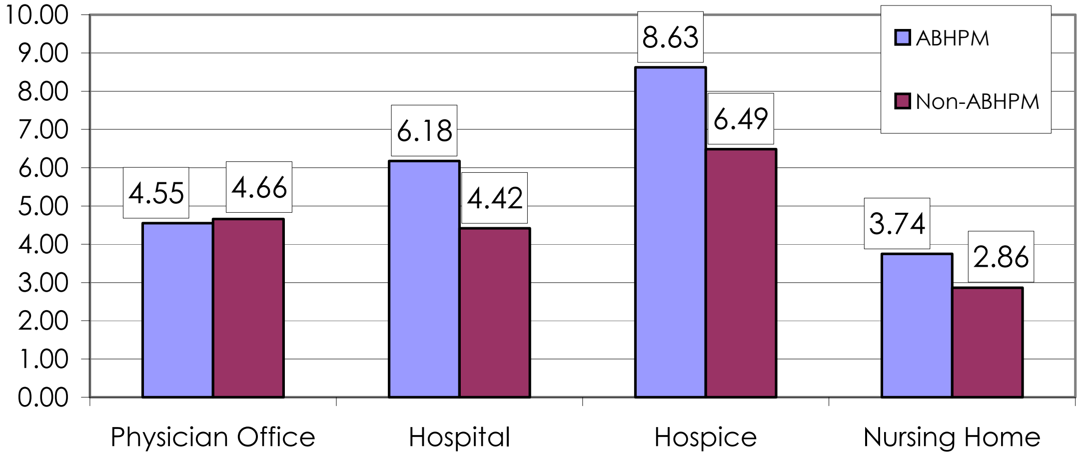
The Roles Performed in Palliative Care Within Current Practice	0-9 Hours	10-19 Hours	20 or More Hours
Medical Director of hospice	77.9%	70.1%	76.5%
Direct Patient Care	57.6%	85.4%	86.7%
Consultant to other health professionals	45.4%	62.0%	71.8%
Coordinate palliative care team	39.5%	58.6%	71.4%
Administrative	29.0%	37.3%	61.3%
Consultant to other MDs	21.8%	47.1%	66.7%
Attend policy and clinical committees	28.7%	36.6%	60.6%
Teaching	15.2%	39.0%	60.4%
Medical Director of Palliative care service	13.5%	23.5%	45.1%
Conduct home visits	12.2%	24.7%	44.1%
Public education	5.7%	10.8%	25.1%
Other	3.5%	13.6%	36.8%
Research	1.9%	5.2%	18.5%

With the exception of medical director of a hospice, ABHPM certified physicians and physicians committing more hours to palliative care each week are more likely to perform the range of roles identified. Non ABHPM certified physicians and physicians working 9 or fewer hours weekly in palliative care were the most likely to hold positions as medical directors of hospice programs. It should be noted, however, that serving as medical director of a hospice is a significant role for all physicians in all categories.

Respondents who have ABHPM certification or who work 20 or more hours in the field are the most likely to direct care, conduct research, teach, consult, and participate in public education activities. Approximately half of the respondents with ABHPM certification report teaching among their roles as compared to one fifth of the physicians who are not certified. Physicians working 20 or more hours in the field are more than twice as likely to serve as consultants to other MDs (66.7%) and attend clinical policy meetings (60.6%) than physicians working 9 or fewer hours (21.8% and 28.7% respectively). These physicians also are more than three times as likely to teach (60.4%) and to serve as Medical Director of a palliative care service (45.1%) than physicians working 9 or fewer hours weekly (15.2% and 13.5% respectively).

More physicians report working in hospice settings (87.3%) for some portion of their palliative care practice than any other worksite type. Other worksites reported include hospitals (77.6%), physician offices (70.9%), and nursing homes (59.1%). Within each of these settings, the majority of palliative care physicians commit 9 or fewer hours to palliative care practice.

Figure 12. Average Weekly Hours Spent with Palliative Care Practices In Different Worksites



Palliative care physicians are most likely to receive referrals to their palliative care practices from physicians with backgrounds in Family Practice (83.5%), Internal Medicine (83%), Oncology (81.9%), and Geriatrics (63.8%). ABHPM certified physicians report receiving more palliative care referrals from other doctors than do non ABHPM certified physicians. Physicians working 20 or more hours weekly in palliative care report receiving more referrals from physicians than physicians working fewer hours. Referrals from specialists trained in the same field as the palliative care physician are not consistently higher or lower than referrals to palliative care physicians from physicians trained in other specialties.

Registered nurses (89%), social workers (85.3%) and chaplains (77.7%) are the staff that physicians most frequently reported working with "routinely" in their palliative care practices.

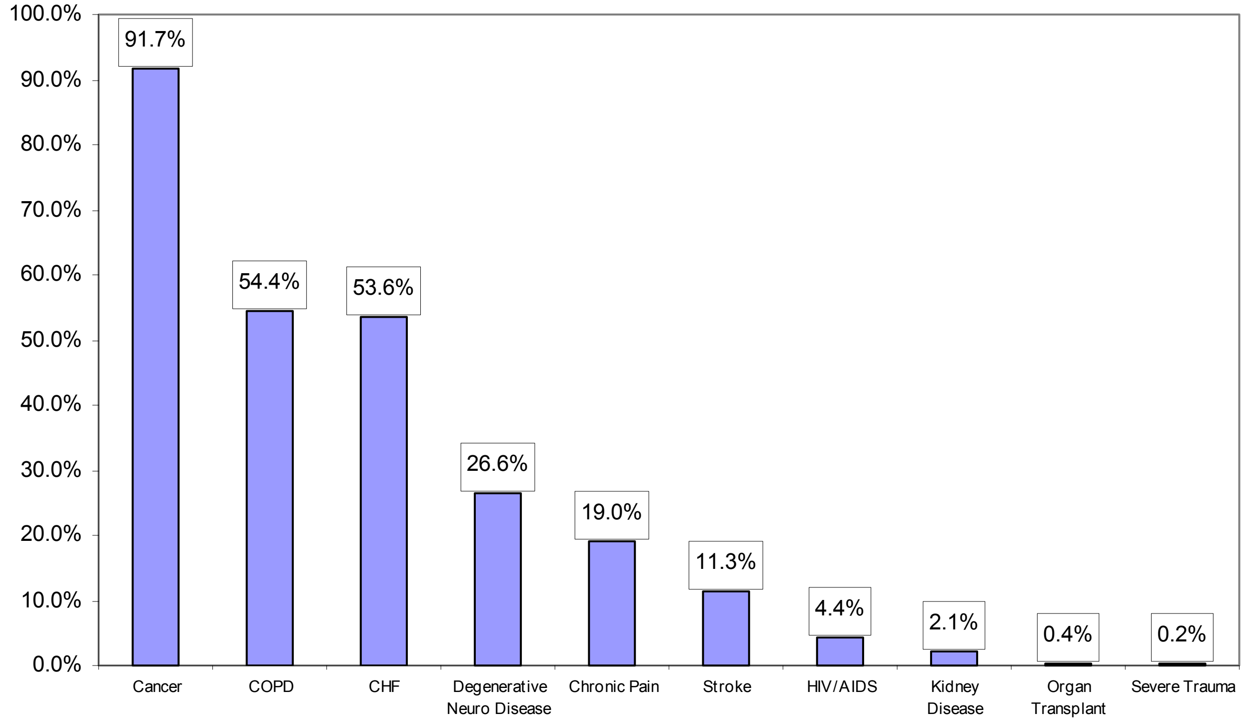
Tables 7. Staff Who Physicians "Routinely" Work With in Palliative Care Medical Practice

Personnel	ABHPM	Non-ABHPM	0-9 Hours	10-19 Hours	20 Hours or More
RNs	89.1%	89.5%	86.9%	95.3%	95.2%
Social Workers	86.9%	84.3%	81.9%	90.1%	94.9%
Chaplins	78.6%	77.0%	73.0%	80.2%	90.7%
Other physicians	74.2%	62.6%	59.3%	72.7%	82.7%
Pharmacists	66.3%	60.0%	53.2%	71.1%	78.2%
Nurse practioners	41.9%	30.1%	25.7%	39.1%	51.6%
Physicians certified by ABHPM	34.1%	8.4%	8.7%	17.4%	41.3%
Nutritionists	33.5%	31.6%	25.3%	40.3%	42.3%
Psycologists	22.2%	20.6%	17.5%	23.7%	29.2%
Physician assistants	16.1%	14.7%	12.8%	15.4%	20.8%
Other	12.3%	10.1%	7.6%	11.5%	17.9%
Alternative Medical Providers	10.1%	7.5%	6.7%	7.5%	13.8%

5. Patients Served

Physicians were asked to identify the three most common diagnoses affecting patients seen within their palliative care practices. Cancer, Chronic Obstructive Pulmonary Diseases (COPD) and Congestive Heart Failure (CHF) are the diagnoses of the majority of patients receiving these services.

Figure 13. Most Common Diagnoses of Patients Provided Palliative Care Services



Only 4.4% of the physicians identified HIV/AIDS as a common diagnosis among their palliative care patients. Approximately 40% of the respondents did not treat any patients with HIV/AIDS within their palliative care practice, and just over half (53.4%) reported that HIV/AIDS patients constitute from 1-5% of their practices.

Physicians treating HIV/AIDS patients are more likely to be ABHPM certified physicians than non ABHPM certified physicians, and they are more likely to work 20 or more hours weekly in palliative care as compared to 0-9 hours per week. Both male and female physicians treating HIV/AIDS patients are more likely to work 20 or more hours weekly than respondents working 0 to 9 hours weekly (male 78.3% to 48.2%; female 77.5% to 43.6%). There is no significant difference in age distribution among respondents providing or not providing this care.

Figure 14. Extent to which Physicians Treat HIV/AIDS Patients in Their Palliative Care Practice: Board and Non-Board

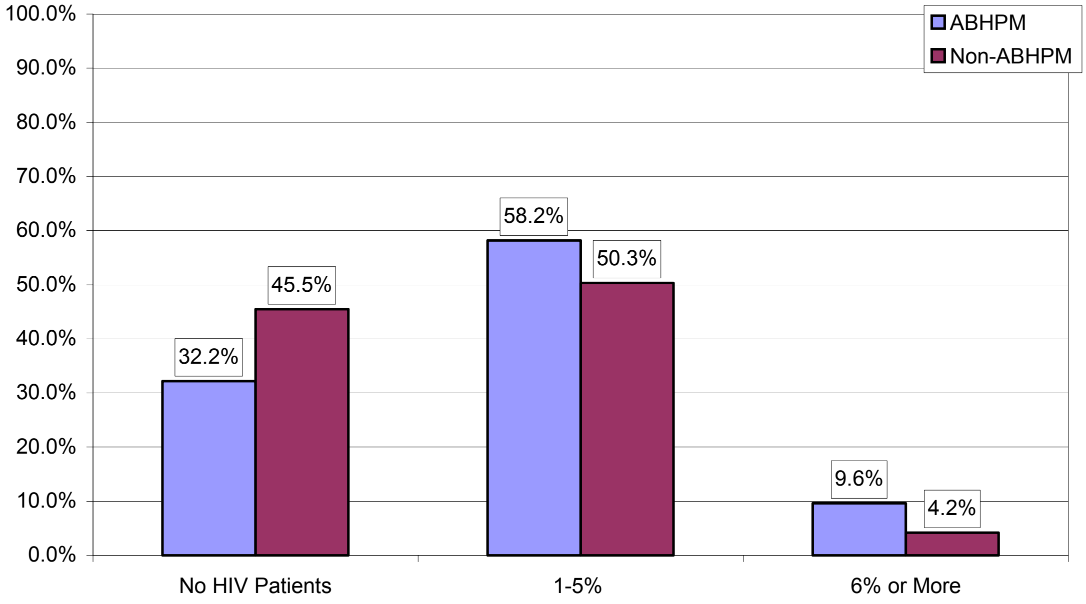
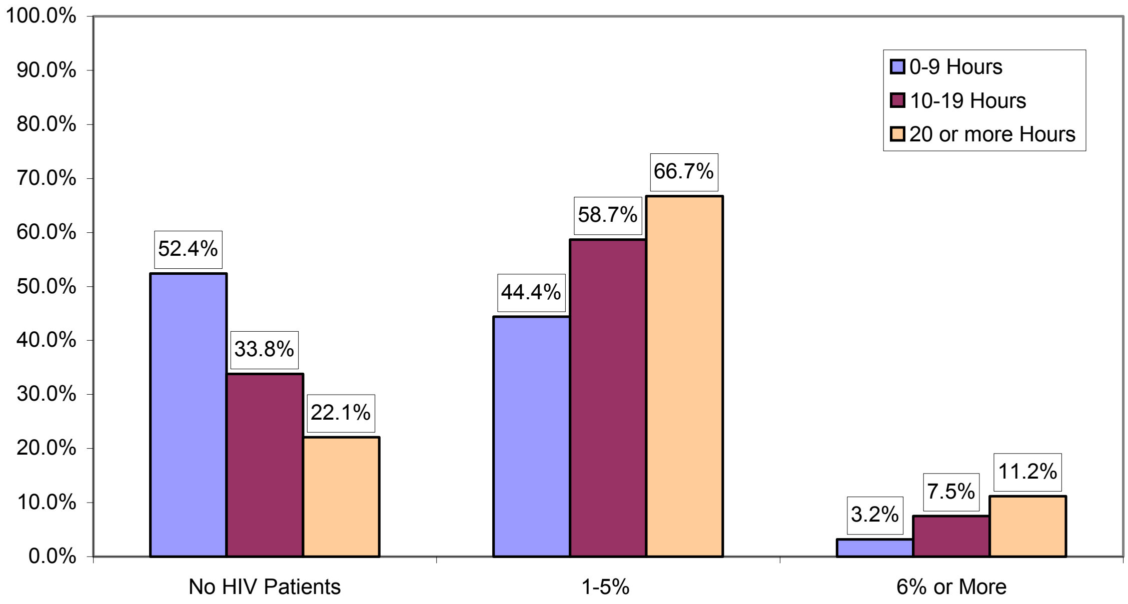
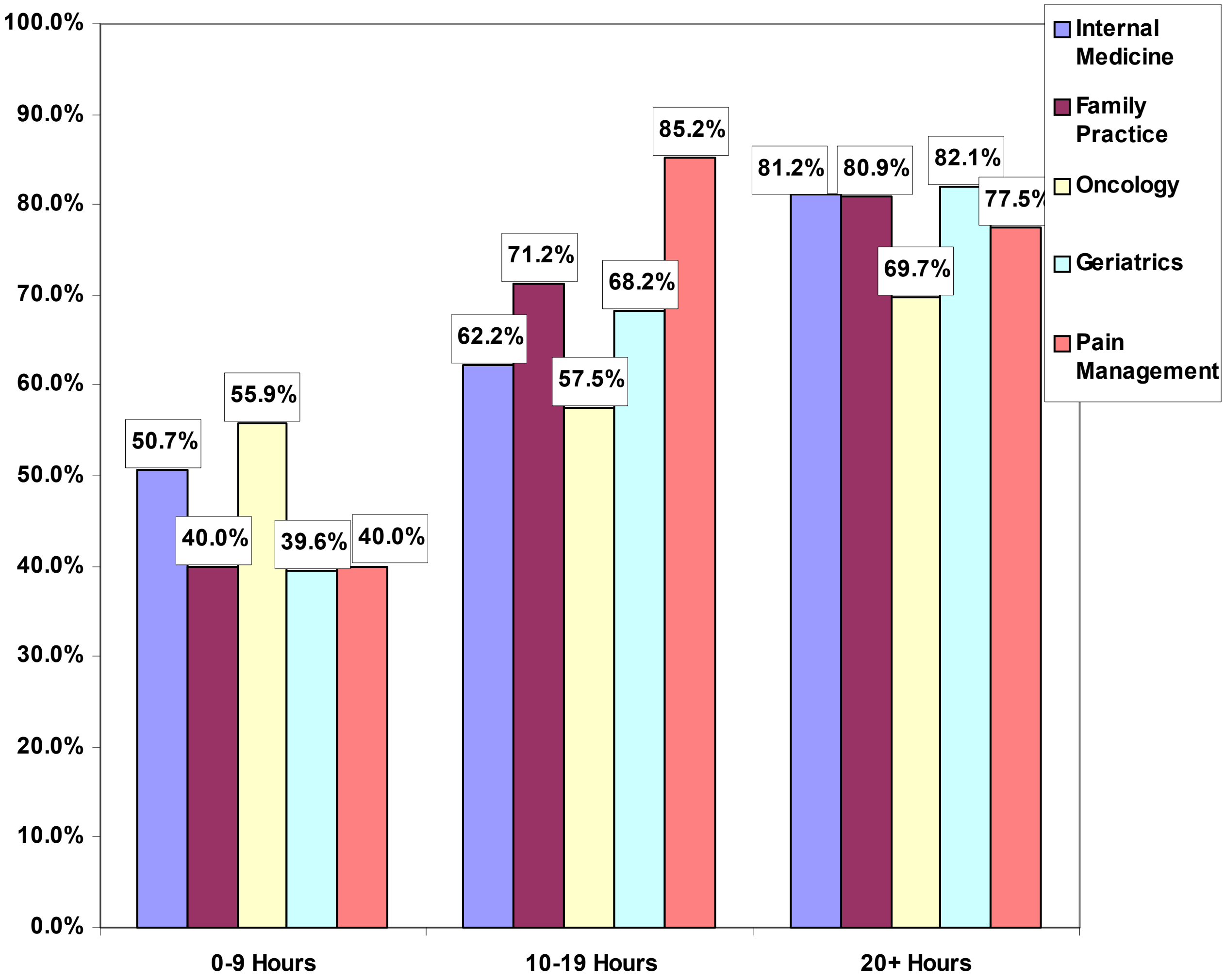


Figure 15. Extent to which Physicians Treat HIV/AIDS Patients in Their Palliative Care Practice: Hours Worked Per Week



Respondents trained in Internal Medicine constitute one third (34.2%) of the doctors providing palliative care to patients diagnosed with HIV/AIDS. Respondents trained in Family Medicine constitute approximately one fifth (19.8%) of these physicians. Physicians specializing in Internal Medicine, Family Practice, Geriatrics and Pain Management who commit 20 or more hours to palliative care are more likely to treat HIV/AIDS patients than their respective colleagues working 0-9 hours weekly in palliative care. The figure below illustrates the percentage of those physicians treating some HIV/AIDS patients (60% of all respondents) in their palliative practice by specialty and hours committed to their practices.

Figure 16. Specialties Treating HIV/AIDS Patients



6. Reimbursement

Fewer than one fifth of all respondents (22.3%) felt that current reimbursement for palliative care services was adequate or generous. The majority of physicians (62.1%) reported that they did not feel that they could earn an adequate living if their practice were limited to palliative care at the current reimbursement levels. ABHPM certified respondents (18.8%) were more likely to report that they could earn an adequate living from palliative care than non ABHPM certified respondents (7.1%). Physicians working 20 or more hours in palliative care were more likely to report that they could earn an adequate living in palliative care (33.9%) than physicians working 9 hours or less in palliative care (3.2%).

ABHPM certified respondents are more likely to receive full payment for palliative care services provided to patients than non ABHPM certified respondents (35.7% to 22.2%). Physicians working 20 or more hours weekly in palliative care were more likely to receive full payment than physicians working 9 hours or less (41% to 21.8%). Approximately a quarter of the respondents report receiving no compensation for palliative care provided to patients. Of these physicians, 26.5% volunteer. Non ABHPM certified physicians are more likely to volunteer than ABHPM certified physicians (27.6% to 12.4%,). Physicians working 9 or fewer hours in palliative care weekly are more likely to volunteer than physicians working 20 or more hours in palliative care weekly (31.7% to 9.8%).

Almost 60% of respondents reported that they derive 20% or less of their total income from palliative care. 11.6% derive their total income from the practice of palliative care.

Figure 17. Percent of Practice Income Derived from Palliative Care Practice: Board and Non-Board

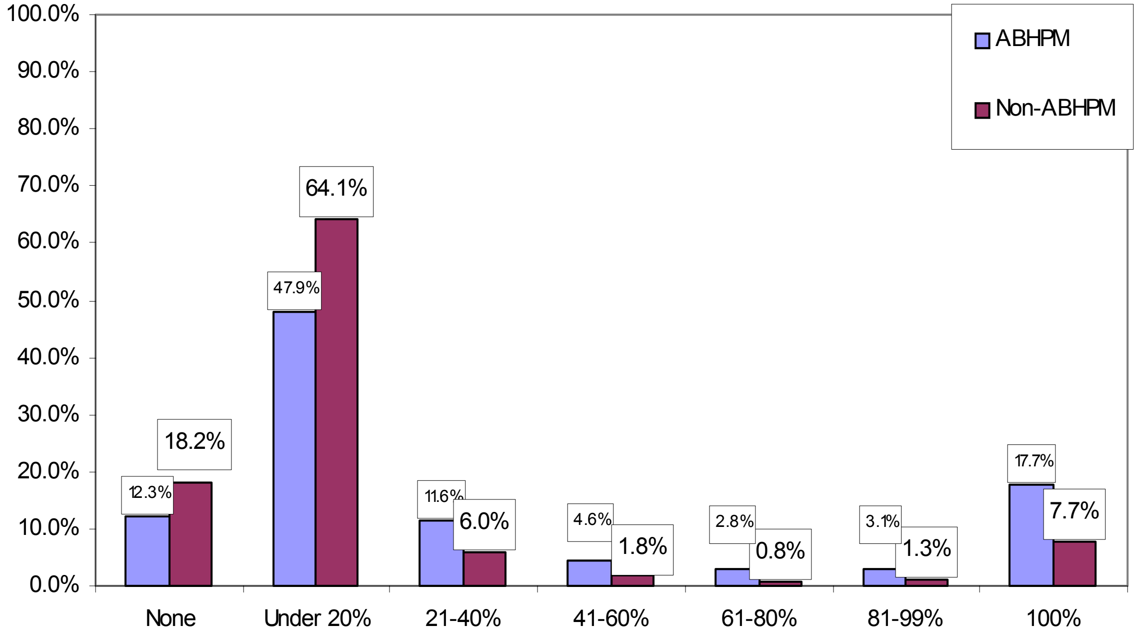
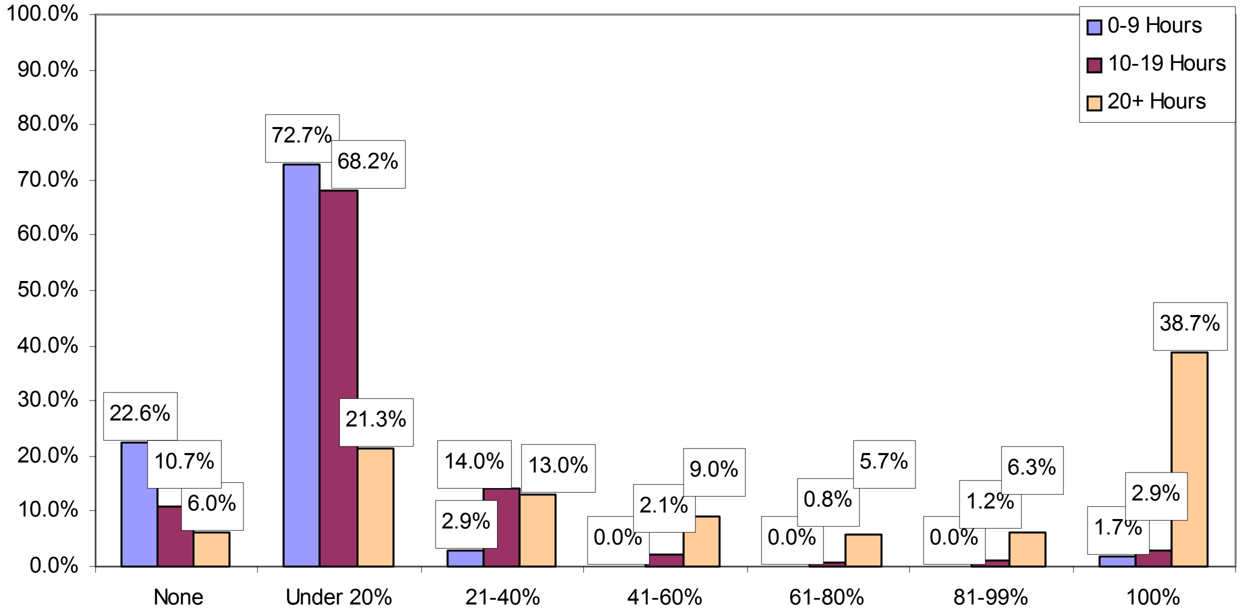


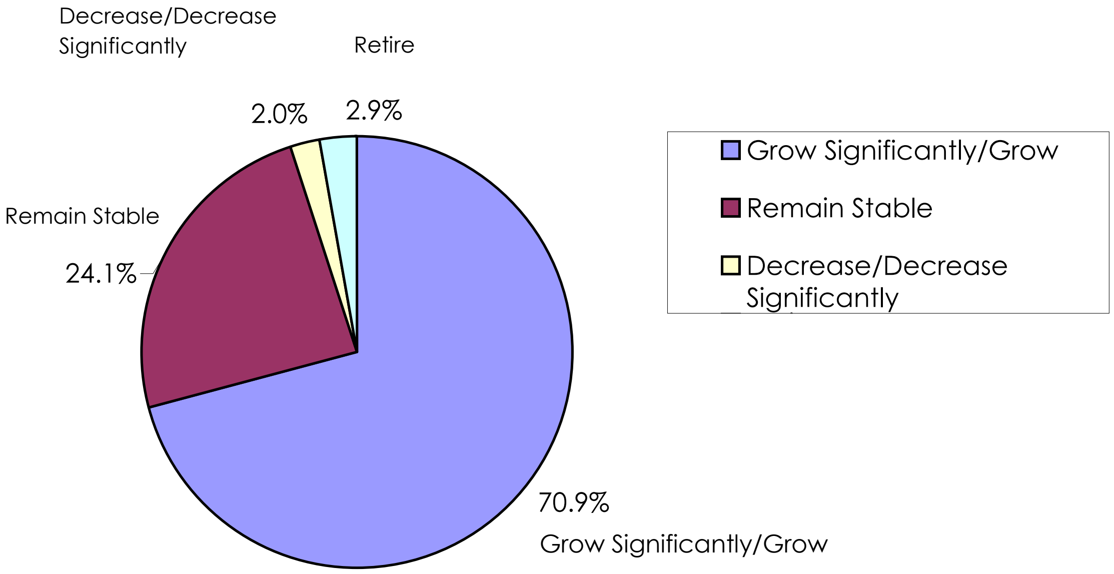
Figure 18. Percent of Practice Income Derived from Palliative Care Practice: Hours Worked Per Week



7. Assessing the Marketplace

Almost 71% of all respondents anticipated that their palliative practices would grow over the next three years. Only 2% expect that their palliative care practices will decrease, and 2.9% reported plans to retire.

Figure 19. Anticipated Growth in Palliative Care Practice over the Next Three Years



ABHPM certified physicians (male, female, and in every age group except for 34 and under) were more likely to anticipate "significant growth" in their palliative care practices than non ABHPM certified respondents. Physicians working 20 or more hours per week in palliative care were almost four times as likely as physicians working 9 or fewer hours weekly to anticipate "significant growth" in their palliative care practices.

ABHPM certified physicians (40.2%) reported more current palliative care practice opportunities in their communities than non ABHPM certified respondents (29.5%). Physicians committing 20 or more hours per week in palliative care (46.6 %) reported more current practice opportunities than physicians committing 9 or fewer hours per week (26.2%). Non ABHPM certified physicians (19%) were more likely to report no opportunities than ABHPM certified physicians (13.2%). Physicians working 0-9 hours (24.2%) were almost three times as likely to report no opportunities than physicians working 20 (8.8%) or more hours in palliative care.

ABHPM certified physicians between the ages of 34-54 were more likely to report "many or some" practice opportunities than non ABHPM certified respondents within this age range.

ABHPM certified physicians (32.4%) were more likely to think that the current marketplace and reimbursement system could support additional physicians trained in palliative medicine in their communities than non ABHPM certified physicians (18%), as were physicians working 20 or more hours weekly in palliative care (38.1%) in comparison to physicians working 9 or fewer hours (16.9%).

8. Adequacy of Supply of Palliative Care Physicians to Meet Needs of Patients and Families

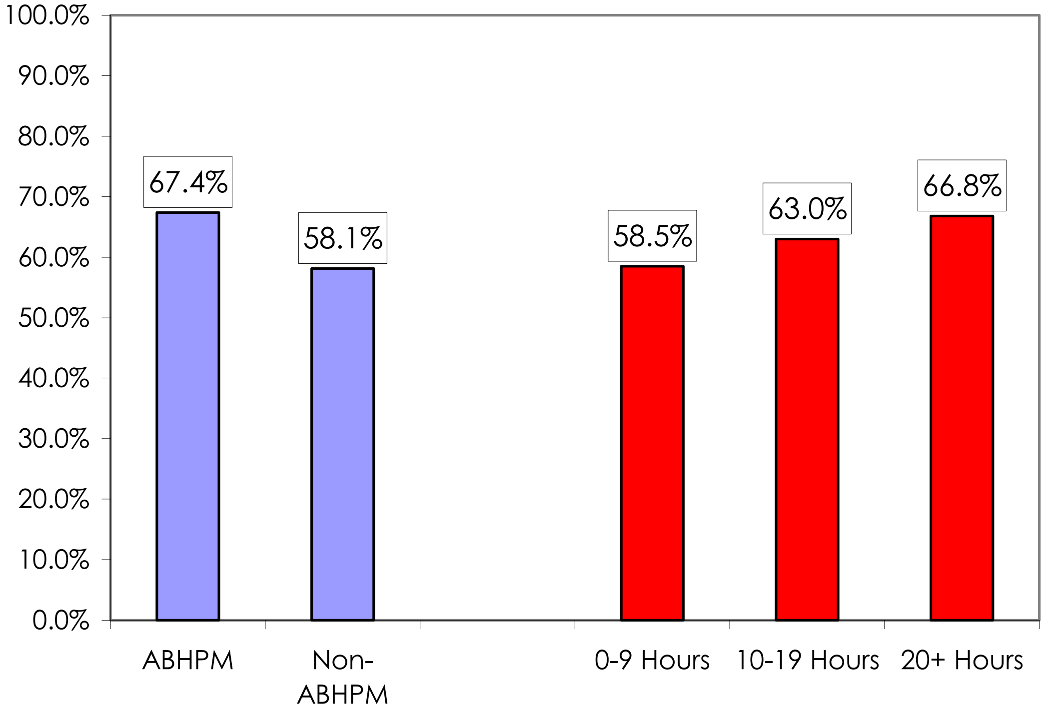
Over half of all respondents felt that the supply of physicians providing palliative care was insufficient to meet the needs of patients and families. ABHPM certified physicians (64.2%) were more likely to see the supply of palliative care physicians as insufficient to meet the needs of patients and their families than non ABHPM certified physicians (47.8%). Physicians working 20 or more hours in palliative care (71.4%) were also more likely to see the supply of physicians as insufficient as compared with physicians committing 0-9 hours to palliative care (47.2%). The time spent in the practice of palliative care may influence perspectives and insights into existing needs.

Perceptions of the adequacy of the supply of palliative care physicians to meet the needs of patients and families were further analyzed by region. ABHPM certified physicians were more likely to report insufficiencies in the Middle Atlantic, East North Central, West North Central, South Atlantic, Mountain and Pacific regions of the country than non ABHPM certified physicians. Physicians working 20 or more hours per week in palliative care were more likely to report the supply insufficient than respondents working 9 or fewer hours per week in all regions of the country except the South Atlantic, where no significant difference exists.

9. Strategies Promoting the Delivery of Palliative Care Identified by the Respondents

*Improving the quality of education and training for **all** physicians* is the workforce strategy most frequently identified by respondents as being “very important” for promoting more effective palliative care in the United States (61.8%).

Figure 20. Physicians Who Regard Improving the Quality of Education and Training for All Physicians as Very Important



Pain management, communications (with patients, families and staff), the process of dying and symptom management were topics physicians deemed essential in palliative medicine education and training programs. Experiential learning, lectures, use of case studies, rounds, and supervised practice are the learning formats physicians believe to be most effective for teaching this subject area.

Other general strategies identified by respondents to improve palliative care include:

- *Increase public education on palliative care* (59.3%).

  "An informed public will be the most powerful force to change end of life care," noted one physician. Respondents' comments stressed the importance of public debate on care for the terminally ill. "Death is not optional. Promoting acceptance of death as part of life will lead to support of more palliative care services for patients and families." Public education was seen by physicians to be a means to promote delivery of more effective palliative care and, in so doing, influence physician, hospital and other provider practices.

- *Expand/improve financing for palliative care services* (55%).

  The adequacy of funding for palliative care services was also identified as a powerful determinant of physician practice.

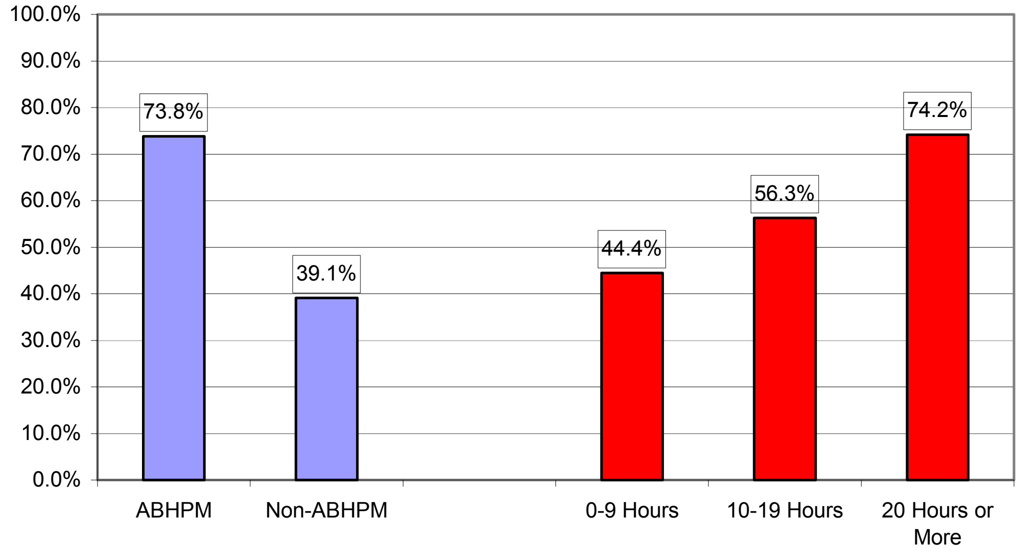
  Low reimbursement rates for physicians were thought to deter individuals who might otherwise provide more palliative care. Physicians commented that current reimbursement practices favor procedures over cognitive activities. Some thought that without changes in reimbursement levels, physicians would not divert significant time from lucrative procedures to provide services such as home visits, which could keep patients out of hospitals or other health care settings and contribute to the quality of their life. Several physicians report that they are only able to provide palliative care because of philanthropy provided to their facilities or the generosity of their employers.

  In addition to dissatisfaction with professional fees, physicians viewed coverage by Medicare, Medicaid and other insurance for specific services, medication and pain management to be inadequate. The need for funding to support palliative care teams, including social workers, chaplains and nurses, was also mentioned.

10. Development of a Formal Medical Subspecialty

Survey respondents favored the development of a formal medical subspecialty in palliative medicine with 54.5% responding yes; 27.2%, no; and 18.3%, no opinion. ABHPM certified physicians were much more likely to favor formal certification than non ABHPM certified physicians (73.8% to 39.1%). Physicians working more hours in the field each week were also more likely to support formal specialty status (20 hours or more, 74.2%; 10-19 hours, 56.3%; and 0-9 hours, 44.4%).

Figure 21. Favor Formal Subspecialty in Palliative Care Medicine



Male and Female ABHPM certified physicians were equally supportive of establishing a subspecialty in palliative medicine (75% to 77.6%), while male non ABHPM certified respondents were less likely to support a subspecialty than female non ABHPM certified physicians (38.7% to 48.6%). ABHPM and non ABHPM certified physicians ages 44 and under were more likely to support a subspecialty than ABHPM and non ABHPM certified physicians aged 45 and older.

ABHPM certified physicians highly favor the development of a medical subspecialty *irrespective* of their views of the marketplace and the reimbursement system's ability to support additional palliative care physicians in the community, or their views of adequacy of the supply of physician to meet need of patients and their families. Non ABHPM certified physicians who view the marketplace and reimbursement system as *able* to support additional palliative care physicians in the community favor a subspecialty. Non ABHPM certified physicians who regard the supply of physicians in their communities as insufficient to meet the needs of patients and their families are more likely to favor a specialty than those who do not.

ABHPM certified physicians who expect their palliative care practices to expand are more likely to favor a subspecialty (76.9%) than non ABHPM certified physicians who anticipate that their practices will expand (48.6%)

Physicians cite many reasons for favoring specialization in their survey comments including:

> "…it's a unique set of skills that deserves more respect. Now I'm convinced that there are many who could not do it, just like I could never remove a cataract".
>
> "There is tremendous need for consult/support services in hospitals and clinics; essential to develop a specialty within the ABMS to be taken seriously in the future".

> "...it's difficult to practice palliative care outside the hospice model; good to develop a cadre of teachers."
>
> "ABMS recognition is essential to establish credibility as a specialty."
>
> "There should be an equivalent AOA certification, as ABMS is likely to exclude many DO's".
>
> "Palliative Medicine at its best is labor intensive... Requires a unique and definable knowledge and skill set which fellow physicians fail to acknowledge".

Comments opposing creation of a medical subspecialty include:

> "Isn't this what all medicine is about?"
>
> "...other physicians and specialists would be more likely to 'leave it for them' to take care of this".
>
> "A subspecialty may further fragment clinical services".
>
> "Specialty status will make it too exclusive to a small group; may marginalize this care".
>
> "Better to train everyone".
>
> "I do not believe it should be limited to subspecialty training from certain medical specialties".
>
> "Doesn't seem to be a big need for specialties in my geographic area."
>
> "One of the concerns with any additional specialty is the cost in time and dollars to MDs for certification and recertification."
>
> "If you are pushing to get a specialty in palliative care, you will end up limiting the care patients receive."
>
> "As an Osteopathic physician, I have reservations regarding ABMS as becoming the exclusive certifying body for palliative care medicine."

Interest in Follow-up Surveys

The 2001 survey will provide a baseline of information on the supply, demand and use of palliative care physicians. Survey recipients were asked to consider participating in future Internet surveys that may be funded to permit trending of changes in the role played by physicians in this field. Six hundred twenty five physicians, about 50% of the respondents returned forms (including mailing and email addresses) to the CHWS indicating their willingness to participate in future research activities.

B. Survey of Hospitals and Health Systems Providing Palliative Care

1. Background

While community based hospices have long been associated with the delivery of palliative care, hospital based palliative care programs have emerged only recently. The Cleveland Clinic established the first formal hospital program in 1987, and programs have been growing in number across the country since then. A second survey was designed to provide insights into the scope of services provided by these programs and to better understand the role that physicians play in the delivery of formal palliative care within them. With over half the deaths in America occurring in hospitals, understanding the approaches taken by hospitals in providing palliative care to patients with serious medical conditions is essential. The survey also sought to measure support for the development of a formal palliative medicine subspecialty, and to better understand the use of palliative care services by people diagnosed with HIV/AIDS and other chronic diseases.

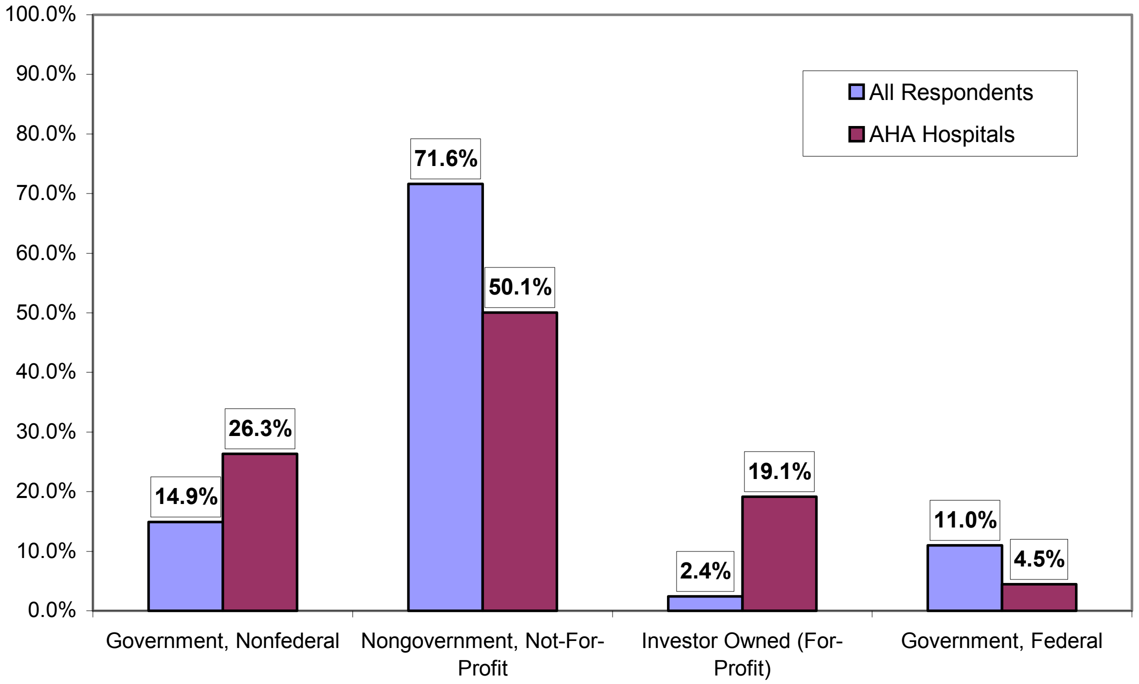
Surveys were distributed to hospitals providing or planning to provide formal palliative care services in their communities in fall, 2001. CAPC provided CHWS with two hospital mailing lists for this effort that were derived from an earlier hospital survey conducted in coordination with the American Hospital Association (AHA). One list included 342 hospitals that currently offer formal palliative care services. The second included 230 hospitals that previously indicated plans to establish a formal palliative care program(s). In summer, 2001, CHWS sent a letter to the contact people identified by hospitals on each list to confirm that they were the appropriate person to receive the upcoming survey. Two hundred twenty nine faxes were returned to us confirming contacts or identifying changes in personnel, address etc. All 572 hospitals were included in the survey.

The targeted hospitals on the survey mailing list were each sent a packet of material which included a joint letter from CAPC and CHWS requesting the hospital's participation in the survey, a four page survey (Appendix C), a form listing definitions of specific types of palliative care programs and a return envelope. Non-responding hospitals were sent up to two additional mailings of the surveys at three week intervals.

A Profile of Hospitals Responding to the Survey

Sixty four percent (64%) of the hospitals contacted responded to the survey. Over 70% of these hospitals are nongovernmental not for profit hospitals. Nongovernmental not-for -profits and Federal government hospitals are over represented among respondents as compared to their distribution among AHA hospitals nationally. (1999 AHA Annual Survey Database).

Figure 22. Hospital Survey: Respondents by Hospital Type.



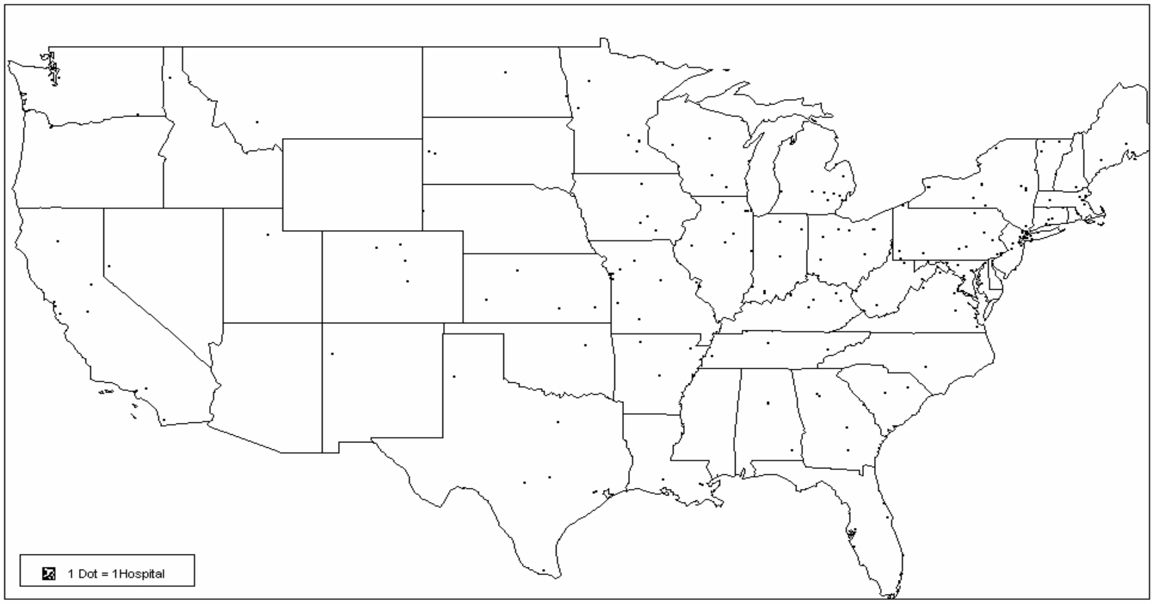
Formal palliative care programs were offered more frequently in larger hospitals, i.e. hospitals with the largest bed complement. Respondents were more than twice as likely as AHA hospitals to have 200 or more beds (57.9 % to 25.1%).

Table 8. Hospital Survey: Respondents by Number of Hospital Beds.

Number of Hospital Beds	Respondents	AHA Hospitals
6-24 Beds	1.7%	7.0%
25-49 Beds	6.5%	19.2%
50-99 Beds	11.9%	24.6%
100-199 Beds	22.3%	24.1%
200-299 Beds	18.5%	11.2%
300-399 Beds	15.4%	6.7%
400-499 Beds	8.1%	2.6%
500 or More Beds	15.6%	4.6%
Total	**520**	**5416**

Survey respondents are more prevalent in the Middle Atlantic, East North Central regions of the country, and less prevalent in West South Central region than the national distribution of AHA hospitals. Respondents were representative of the hospitals surveyed. The map that follows identifies the sites of responding hospitals.

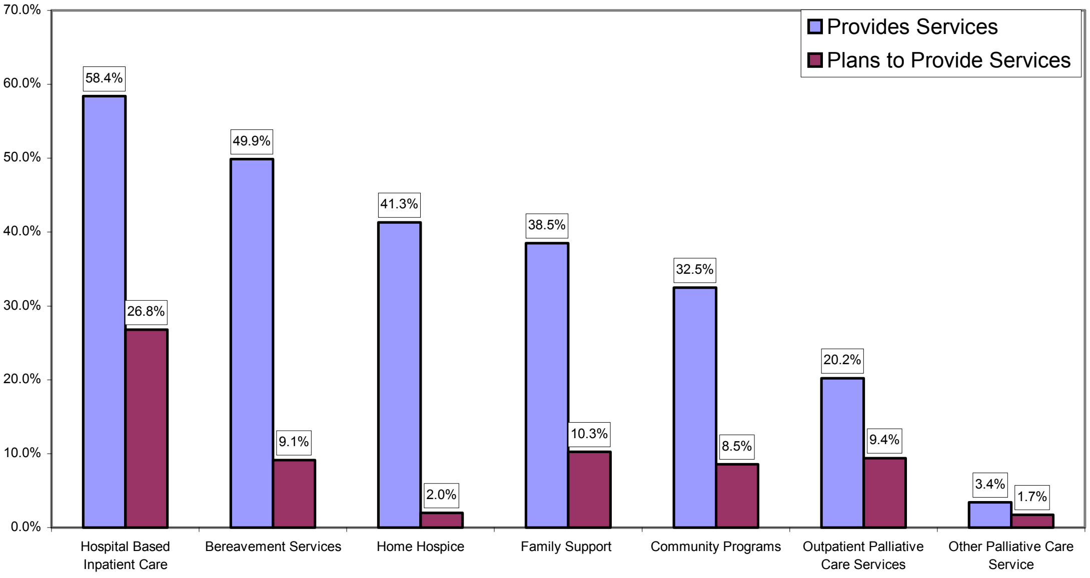
Figure 23. Distribution of Hospitals that Provide or Plan to Provide Palliative Care Services that Responded to the Survey.



2. Services Offered and Projected

76.1% of the hospitals surveyed reported that they currently provide formal palliative care programs or plan to provide such programs in the next 12 months. The types of services currently offered are detailed in Figure 24.

Figure 24. Formal Palliative Care Services Provided by Hospitals



Hospital inpatient programs may include one or more of the range of services listed in Table. 9.

Table 9. Breakdown of Hospital based Inpatient Services

Hospital Based Inpatient Care	Provide Services	Plans to Provide Services
Consultation Services	42.5%	15.1%
Dedicated Inpatient Geographic Unit	10.3%	7.4%
Dedicated Number of Scatter Beds	11.4%	5.4%
Dedicated Inpatient Hospice Unit	15.7%	4.8%
Direct Care in Acute Unit	20.2%	6.0%
Combined Inpatient Hospice - Palliative Care Unit	10.5%	5.7%

Hospitals anticipate growth in these programs over the next 18 months: 76.2% expect that they will increase the number of patients served; 66.8% expect that the types of services offered will be expanded; and 48.4% expect that current services will be redesigned. Only 1.2% anticipated that services would be reduced.

Over 70% of the survey respondents reported having contracts with hospice organizations in their communities. According to the AHA DATA BOOK, 1999, 48.3 % of the respondents provide hospice services, in contrast to 24.2% of the AHA hospitals nationally; 53% of respondents provide end of life services in contrast to 18.9% of AHA hospitals nationally; and 81.8% provide pain management services in contrast to 39.1% of AHA hospitals nationally.

Hospitals that provide or plan to provide formal palliative care services reported providing education and/or training in this area to other physicians (53.6%); residents (44.6%); medical students (36.7%), other health professionals (76%), and other professionals (16.1%).

3. Profile of Physicians in Palliative Care Programs offered by Hospitals

The majority of hospitals reported that one (36.4%) or two (21.7%) physicians currently provide care within formal palliative care programs offered. Slightly over 11% report that ten or more physicians provide services in their respective programs.

Physicians working in hospital programs were described by hospitals as having completed a range of education and training programs in palliative care. Three quarters of the hospitals report that some or all of the palliative care physicians participated in short courses in this area. Over half the hospitals report that some or all of their physicians completed the EPEC training, and one quarter report that some or all physicians participated in the EPEC Trainer Training. Approximately 15% reported that some or all physicians in their programs completed a fellowship program in palliative care, and approximately 25% report that some or all physicians completed residency rotations in this area. *Over 70% of the hospitals indicated that at least one physician in their program has ABHPM certification.*

4. Recruitment of Physicians

General Internal Medicine (59.2%), Pain Management (57.3%) Oncology/Hematology (54.7%), Geriatrics (47.9%) and Family Practice (46.1%) are the backgrounds most hospitals prefer when recruiting new doctors for their palliative care programs. Completion of the EPEC course (73.6%), ABHPM certification (63%) and completion of a fellowship program (61%) are the education and training backgrounds most frequently identified as required and/or preferred for these doctors. The qualifications and skills that hospitals indicated they would seek in a director of a palliative care program are detailed in Table 11.

Table 10. Qualifications and Skills Sought in Physicians Leading Palliative Care Program

Skills	Percent
Interpersonal Skills	75.3%
Pain Management	74.2%
Team Building	62.5%
Educator	57.3%
Recognized Physician Leader	55.8%
Board Certification in a Specific Specialty	41.6%
Disease Management	37.5%
Administrative	34.5%
Public Relations	25.1%
Research	19.9%
Number of Years in Practice	15.4%
Fund-Raising	9.4%

Slightly over half of the hospitals that recruited palliative care physicians over the past year reported success in hiring physicians with the backgrounds sought. Federal government programs were most successful in recruiting palliative care physicians with desired backgrounds (83.3%). Hospitals planning to recruit physicians anticipate hiring one or two physicians.

Over half (53%) the hospitals thought that the current supply of palliative care physicians was insufficient to meet the jobs that are available. Asked if the supply would be sufficient to meet the need in communities with improvement in payment, 29.2% said yes, 35.8% said no, and 35% were unsure. This suggests that reimbursement is an important but not the sole factor that will influence the availability of palliative care physicians. Regional differences were not evident.

5. Financing Palliative Care

Hospital respondents were asked to identify issues related to the financing of palliative care that might encourage or discourage use of physicians in their programs. Several reported the lack of institutional support and resources for the development and operation of palliative care services. This includes limited commitment of funding for full time staff. Factors identified as deterrents to the recruitment of physicians for palliative care programs include: inadequate payment for palliative care services (scope of services covered, level of reimbursement available, lack of DRG designations) to hospitals and to physicians by Medicare, Medicaid and insurance companies; general budget constraints leading to cost avoidance, particularly in areas with limited promise of revenue generation; existing financial and social commitments to the provision of services to large numbers of uninsured patients; and lack of understanding of patients' end of life needs. Physician reticence to refer to palliative care programs was seen to further limit demand for services utilizing doctors. *A national approach to funding palliative care services was thought to be essential to assure access to affordable medication and care provided by physicians and other members of multidisciplinary palliative care teams across the continuum of health care settings.*

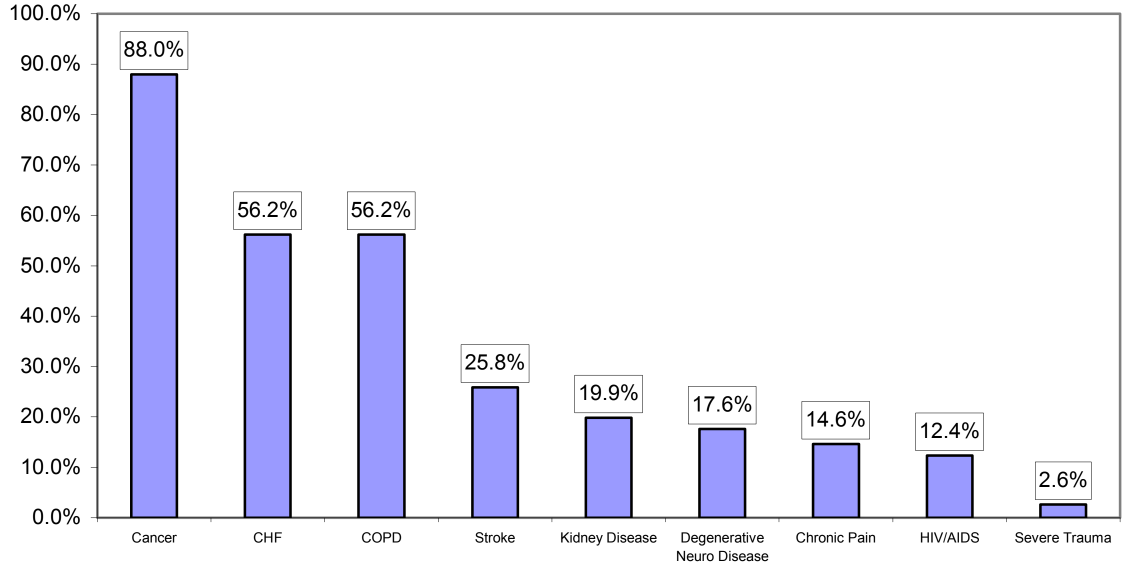
6. Development of a Formal Certification in Palliative Medicine

Hospitals strongly support the development of formal certification in palliative medicine, with 67.3% of respondents favoring, 8% opposing, and 24.7% unsure of certification. Hospital respondents favoring specialty certification cite reasons including: need for effective teaching on care of patients at the end of life (93.8%), consulting resources for other physicians (92.7%), direct care for complicated cases (75.1%), direct care for patients admitted to palliative care programs (63.8%), and research in end of life care (63.8%).

7. Patients Receiving Palliative Care Services

Cancer, CHF and COPD are the most common diagnoses of patients receiving palliative care in formal palliative care programs in hospitals. Figure 6 further details the illnesses reported by respondents. Prognosis (58.4%) and life expectancy (52.1%) were the factors most frequently cited as determining patient eligibility for these programs.

Figure 25. Most Common Diagnoses of Patients in Hospital Based Palliative Care Programs



As noted above, patients with HIV/AIDS were “commonly served” by only slightly over 10% of the responding hospitals. Close to half (47.1%) the hospitals do not report having HIV/AIDS patients in their formal palliative care programs. Close to a quarter of these hospitals (23.1%) report that HIV/AIDS patients constitute 1% of their patient base, while approximately one fifth of respondents (21.2%) indicate HIV/AIDS patients constitute 5% or more of the patients receiving formal palliative care services. There is no difference in the types of hospitals that provide palliative care to HIV/AIDS patients and all hospitals that responded to the survey.

8. Palliative Care Program Staffing

The most frequently mentioned non-physician personnel participating in the delivery of palliative care services include social workers (82.5%), registered nurses (81.3%) and chaplains (77.6%). A more detailed listing of “core” and “available” staff follows. Approximately one third of the hospitals reported that specialized training in palliative care is required for non-physician personnel.

Table 11. Types of Non-physician personnel Utilized in Palliative care Programs.

	Core Team	Not Core But Available	Not Used
Social Workers	82.5%	12.6%	4.9%
RNs	81.3%	10.2%	8.5%
Chaplains	77.6%	15.0%	7.3%
Pharmacists	46.3%	39.8%	13.8%
Nurse Practitioners	34.6%	14.2%	51.2%
Nutritionists	34.6%	47.6%	17.9%
LPNs	26.8%	20.3%	52.8%
Alternative Medicine	14.2%	32.5%	53.3%
Psychologists	14.2%	39.0%	46.7%
Providers	12.6%	8.1%	79.3%
Other	8.9%	2.4%	88.6%
Physician Assistants	2.8%	11.4%	85.8%

9. Strategies Promoting the Delivery of Palliative Care

The workforce strategies most frequently identified by hospitals as being “very important” to promote more effective palliative care in the United States are:

- Improving the quality of education and training for ALL physicians (75.9%) and
- Increasing the supply of other health professionals with palliative care training (56.8%).

General strategies that hospital respondents perceived as critical for assuring improved palliative care include:

- Expanding/improving financing for palliative care services (79.5%).
- Increasing public education on palliative care (70.2%) and

- Establishing quality of care standards for palliative care (52.4%).

Respondents noted that developing new programs can take several years from inception to implementation. Educating hospital administration about benefits was thought to be critical to garner the institutional support necessary to assure resources for programs.

Hospital respondents cited need for culture change generally around death. Education of patients and families to increase their understanding of the dying process was thought to be important, as was improving communication around quality of life issues.

C. Interviews with Medical School Educators on Preparation of Physicians in Palliative Medicine

Medical schools play a central role in the development of physicians' knowledge, skills and values. For this reason, obtaining information from medical educators on how palliative medicine is addressed within their medical education programs was a key component of the study on the Supply, Demand and Use of Palliative Care Physicians in the United States. Structured interviews with medical educators were conducted which helped clarify perspectives on: the role medical schools play in introducing and developing physician understanding of and skills related to palliative care; preferred approaches for educating and training physicians in palliative care, and potential roles for physicians with training in palliative medicine.

The Center for Health Workforce Studies (CHWS) identified a random sample of twelve allopathic and osteopathic schools to be surveyed through half hour structured telephone interviews. In summer, 2001 letters were mailed to each of the schools describing the project and asking to interview the Dean or his/her designee. Ten of the 12 schools agreed to participate in the research. (8 percent of the total U.S. medical schools.) The interviews were conducted with individuals designated by each school including, Deans and Associate Deans for Medical Education, Undergraduate Medicine or Academic Affairs.

KEY FINDINGS*:*

Medical educators believe that a core body of knowledge in palliative care exists and should be taught in medical school. Clinical years were regarded as particularly important in influencing the approach, attitudes and skill development of new physicians.

Challenges in incorporating palliative care into medical education were attributed to difficulties in altering medical curricula in general, rather than as a result of resistance to addressing this issue.

Medical educators were generally undecided regarding the desirability of formal certification in palliative care through the American Board of Medical Specialties. They did believe that roles of physicians with expertise in this area included educator, medical consultant and/or direct care provider, director of palliative care program, policy maker and researcher.

Medical educators emphasized the importance of increased education in palliative care for all physicians. They emphasized the importance also of continuity of care, assuring that physicians maintain contact with their own patients throughout the course of their illnesses.

How Do Medical Schools Currently Educate Physicians in Palliative Care?

Participants were asked to describe how their medical schools currently address palliative care and end of life issues within their curricula and programs. Eight described their palliative care initiatives as already "integrated" into their medical school programs while 2 schools described their program initiatives as "new". Only one of the ten schools felt that current initiatives were adequate.

All of those interviewed believed that a core body of knowledge on palliative care exists, should be taught in medical school, and should be threaded across medical school training.

Several deans indicated that it was important to address attitudes and approaches, not just skills, to prepare physicians for assisting patients who are dying. The clinical years were cited as particularly important for expanding the awareness and skills of students in providing palliative care to patients and their families. Clinical experiences also were recognized as strongly influencing future practice patterns. Three deans stated that they personally would be hard pressed to describe what should be included in the core body of knowledge, and different deans emphasized different components as the focus of study, e.g. pain management, communications, ethics and professionalism.

Medical schools varied in their approaches to integrating education on palliative care into their programs. Three schools were attempting to build a longitudinal integration of palliative care into their curricula having identified palliative care as a theme crossing all teaching. Other schools were concentrating on building specific programs that are either tied to specialty areas or to the development of palliative care clinical units in hospitals and/or hospices. The range of educational strategies embraced by schools included introducing palliative care issues in Year One and/or Year Two course work; providing clinical rotations in years three and/or four where formal study of related clinical practice issues are required; offering electives where palliatve care issues are addressed, viz. ethics, legal issues, and "interclerkship" end of life courses; requiring short term problem-solving courses and communications courses; and supporting informal, noncredit courses where emerging clinical and social issues are discussed with community and faculty physicians. One dean stressed the challenge of helping students to continue to build on the skills learned as they progressed through their medical education.

Three medical schools have appointed specific individuals to lead the effort to incorporate palliative care into their programs. Each of these individuals also heads the palliative care unit in a hospital where the school directs some of its students for clinical experience. (Two of these 3 individuals were only recently appointed.) Other deans reported that palliative care was a crosscutting issue and that a number of faculty from several specialty areas were interested and active in building their schools' palliative care curricula. These faculty members took responsibility for leading focused efforts, e.g. building a required palliative care component into a clinical rotation.

Deans reported that it was too early to provide outcome data on the impact of their palliative care educational initiatives. One school's dean stated that palliative care would be regarded as a competency area that students will be tested in. Another indicated that his school would measure the impact of identifying palliative care as a "theme" to determine if the desired impact is achieved. Six schools stated there were no formal measures of palliative care training consistently in place. Examples of outcome measures that several schools reported having in place or considering include: tracking graduate perspectives on AAMC questionnaires; assessing student performance on tests in courses where palliative care issues and/skills are covered as well as through clinical performance exams; and reviewing student self assessments.

When asked what future directions their programs will be taking, or directions they would like to see their schools take, five deans indicated that adding formalized course work within the clerkship years was desirable. Deans emphasized the challenge of incorporating or weaving study of these issues throughout several departments. One educator believed that his university hospital would be establishing palliative care protocols and that this system change would assist in training physicians. One dean believed that assigning faculty within a geographic area in his hospital would help build the school's program. One hoped to find someone to take ownership of the issue, to be sure that students are taught these issues. Other deans recognized that grants might be pivotal to their ability to build new initiatives.

Challenges in Incorporating Palliative Medicine into the Medical School Programs

Eight of the 10 medical schools identified the general difficulty in changing the core curricula as the primary challenge for introducing any new issue into medical school education, including palliative care. No school reported resistance from faculty specific to addressing palliative care issues. In fact, all reported support for increased focus on teaching palliative care with several schools reporting "unusual agreement" on the importance of these issues.

Some educators believed that they would be most effective in integrating palliative care training into the curricula if the material introduced is tied into a more general curricula restructuring effort. In some cases deans anticipated that their schools would be undertaking such efforts and would be able to build palliative care components in tandem with these changes. Several schools indicated that they currently identified palliative care as an "emerging issue" and focused on these issues in special courses. These deans reflected that they would need to assure continuity by incorporating such emerging issues into the core curriculum as other "new" issues emerged.

Deans noted that faculty members are sensitive to the "time" devoted to any new area of study and to the consequent impact on teaching time available for other substantive areas. Deans also noted that "the availability of reimbursement" for faculty who are asked to incorporate new material into their courses is another concern affecting faculty involvement and support. Also, some voiced concern that some individuals on their faculties may not be as strong in their own palliative care skill sets as they could be.

Other challenges reported by schools in establishing palliative care educational opportunities include: the distance of hospices to medical schools; lack of palliative care hospital units where students would have opportunities to participate in clinical experiences; limited access to clinical role models; and the need to understand and make care responsive to multicultural communities.

Student Interest in Palliative Care

All medical schools reported that students were receptive to addressing quality of care issues for patients with serious medical conditions. At some of the schools, students have been instrumental in establishing and running courses, seeking out or creating clinical rotations, and encouraging more focus on palliative care. One school reported that "students as a whole" are interested in this issue. Several others report that it is a smaller subset or "healthy minority" of the student body that is interested. Two schools suggest limited interest and/or follow through by students in attending palliative care electives. The magnitude of what needs to be covered in medical school is believed by some deans to overwhelm students' ability to participate in electives and other offerings.

Interestingly, one medical school's dean described the popularity and demand for an Ethics Elective that students coordinate in which end of life issues are addressed. Another dean reported that he just discontinued their school's Ethics elective, which also focused on these issues, because students did not show up for the course. This school will be changing how this course work is incorporated into its program.

Community Support

Several schools reported strong support for their palliative care initiatives from their communities. This is demonstrated through contributions of resources supporting multi-disciplinary professional training efforts and community physicians volunteering time on committees or to train students in academic and clinical settings. State legislative mandates also affected the direction of some schools in developing palliative care initiatives.

Opportunities for Physicians in Palliative Medicine

Deans were asked whether they believed there would be expanding opportunities for physicians interested in focusing on palliative medicine. Five thought that opportunities would increase; one thought they would not; and four were unsure of implications for practice. Those seeing greater opportunity cited public demand for improved care; the need for experts in palliative care in research, academic and practice settings; the inefficiency and cost of relying on current end of life interventions with poor outcomes; and physicians' entrepreneurial spirit leading them to niches where they can build their practices. They also cited the need for institutional leadership in this area. The Dean projecting limited practice opportunity felt that current or future funding would not support this direction.

Several distinct roles were identified for physicians trained in palliative medicine including: educator, medical consultant and/or direct care physician, director of palliative care programs, researcher, and policy maker and administrator.

Seven deans saw a need for physicians able to train others in palliative medicine during the four years of medical school. While several voiced the desirability of having physicians with palliative care expertise on the faculty, they indicated that palliative care expertise would be in addition to or developed within the faculty members other specialty training. One dean opposed any certification requirements that precluded excellent faculty interested in teaching in this area from doing so.

Six deans believed palliative care physicians could “consult” with other physicians, assisting them with difficult cases, or facilitating care of patients through other physicians. Several emphasized the importance of the role of coordinator across professional disciplines.

The importance of having physicians maintain contact with their own patients even as they consult or refer with palliative care physicians was emphasized by several deans. Six deans believed that palliative care physicians could be involved in the direct care of their own patients and, in some circumstances, could take on the direct care of patients referred to them by others. One respondent adamantly opposed the referral of any patient for direct care by a palliative care physician, emphasizing the need to assure continuity of care for the patient. Others felt that taking on responsibility for direct care from others was important given their experience that some physicians did not want to deal with dying patients and their families. Reimbursement levels were identified as factors that could influence whether or not referrals would be made.

Palliative care physicians were also identified as leaders of programs, such as hospice or palliative care centers, (3); as policy makers helping set practices for institutions and systems (2); and as educators of others, including patients’ families (2). One dean believed that palliative care would be an important area for future research; one dean thought such research would not emerge as a key focus.

Development of Formal Subspecialty

There was no consensus on whether an American Board of Medical Specialties credential (specialty, subspecialty or certificate of added competency) in palliative care should be established. One dean favored creating a specialty in palliative medicine; one dean opposed it. Seven deans were unsure of what to recommend. On the one hand, deans described the usefulness of a credential for adding focus to a subject area and legitimacy for a physician’s expertise. One dean thought a palliative care credential would be an asset when dealing with concerns about pain medication management with others. Others thought a credential might be useful for justifying reimbursement for consultations. But several voiced concern that all physicians needed palliative care training and that the establishment of a specialty might compromise general medical education. They also voiced concerns about further fragmenting medicine, and unnecessarily restricting access to fellowship programs to physicians interested in these issues.

While stating that the need for a specialty or subspecialty area was not clear, several deans indicated that if a credential were to be established, multiple disciplines should be eligible and internal medicine, other primary care specialties, oncology and anesthesiology should be considered as potential pathways.

Other Issues Identified as Important in Improving the Quality of End of Life Care in the United States

Deans were asked to reflect on other issues that impact the quality of end of life care. One or more of those participating in the interviews raised the following issues:

Funding for Palliative Care Services

There is need to provide: adequate reimbursement to attract and sustain physicians interested in practicing palliative care; insurance coverage for medical and related support services; and funding for medical schools to cover costs of training students in this area. Some deans emphasized that reimbursement should cover time spent educating and counseling families.

One dean believed that palliative care should be seen as "already part of the job", and therefore "already reimbursed". Having stated the need for clarification of expectations for physicians, this dean still felt that there was need for additional funding for this area.

Some groups, such as immigrants, are currently excluded from coverage for some services under current federal and state policies. This has an impact on health systems as well as the care and support available to terminally ill people and their families. Addressing such gaps is essential in refining policies and practices.

Regulation and Standards

It was recommended that Medicare regulations governing palliative care be changed. The current policies limited the range and time period of reimbursable services for hospice care. The requirement that an individual be diagnosed as "terminal" and within 6 months of death was seen to inhibit the appropriate use of palliative interventions.

Regulations such as the Joint Commission on Accreditation of Healthcare Organizations (JHACHO) ethics committee requirement were cited as useful in facilitating support for end of life decision making and care. Such forums help to address physician and other health professionals' discomfort and reduce concerns related to liability. Establishing other "standards" was thought to be a means to promote quality of care and foster system change.

Research on best practices was thought by some to be important for influencing the design of service.

Education and Training

Deans identified the need for increased palliative care training for physicians and for other professions. The deans noted that all physicians need an understanding of the basic principles of palliative care. This would be developed through training in medical school as well as continuing education programs, fellowships and residency programs. Expanded roles for other disciplines, e.g. nurses, were also recommended.

Concern was raised about best strategies to reach physicians in mid career.

Several deans also noted the importance of physician awareness of multiculturalism and alternative medicine.

It was recommended that pain management and related prescription issues be incorporated into training and recertification initiatives for physicians.

Technology

One dean emphasized the need to reflect on how far to push technology to prolong life. This dean felt that research and development in technology should not occur in a vacuum. In balancing patient's needs, resources may be better used to respond to managing pain levels rather than turning to high technology.

Patient and Family Education

It was thought that patients, their families and the public at large needed more information on what constitutes good medical care, including end of life care. One dean reflected that high end care in the U.S. is seen as better care, and this may actually interfere with best practice. Discussions of "setting limits" were thought to be desirable by some. Expectations of Americans differ from those of other countries, and such differences should be part of discussions for future care.

Also, community education that would promote greater acceptance of palliative care as a concept was recommended. Public debates on state requirements and discussions of health policies influence what patients and their families see as good care.

Physician Culture

Physicians are trained to save lives. Helping physicians increase their comfort with death and dying was thought to be critical as doctors are relied on to help people set limits and support terminally ill family members. Several indicated that physicians do not want to see patients as "terminally ill" and that this may impede "a good death".

Some deans noted that the visibility of end of life concerns can influence practice. For example, the increased visibility of needs of terminally ill individuals diagnosed with HIV/AIDS occasioned physician willingness to develop practices that better supported patients in their last days. Centers that deal with terminally ill patients are important loci for the development of best practices in end of life care and for training residents and fellows.

Physicians were described as disinclined to make house calls, which can be an important part of care for patients with serious medical conditions. Reimbursement and training would facilitate reemphasis on this role.

Design of Health Systems

It was recommended that health systems be designed to be more responsive to patients needs and to address patients' perceptions, and experiences. This would require a change in how patients are managed.

Some hospital cultures were cited as 'unsupportive of' the establishment of palliative care units due to a "get them out" mentality that pressure staff to discharge patients quickly.

Other Services

Insufficient services exist to support chronically and terminally ill patients and their families. Providing additional levels of care, e.g. home care, were seen as pivotal to providing quality and cost effective care. One dean thought the lack of such services occasioned inappropriate demands on health providers and systems. Better quality indicators evaluating programs, such as hospices, were also mentioned as mechanisms that would support use of such services.

D. Interviews with Leaders from Medical Specialties that Frequently Care for Patients with Chronically Disabling and Terminal Illnesses

Medical boards and physician professional associations address the quality of medical care within their fields of specialization. They do this through the development of physician certification and recertification requirements, training and education programs and the development of standards and best practices. The Center for Health Workforce Studies interviewed representatives of 8 professional associations/ societies to gain a perspective on how palliative care issues are currently addressed within specialties that commonly care for patients with chronic and terminal illnesses. The specialties contacted included: Cardiology, Family Practice, Gerontology, Infectious Diseases, Internal Medicine, Oncology, Pain Management and Pediatrics.

Letters were mailed to the heads of each professional organization describing the physician workforce study and requesting the opportunity to schedule a half hour structured telephone interview with the CEO or his/her designee. Interviews were held in summer, 2001 with seven of the eight specialty organizations. One association asked that we speak with two physicians, which we did.

Interviews were conducted with CEOs/ Executive Vice Presidents, board members, committee chairs, as well as direct care physicians who were regarded as having significant expertise in palliative care. The responses therefore include a mix of institutional and direct care perspectives. Respondents were very open in sharing their views, though several reflected that they were not “expert” in all that may be occurring within their area of specialization.

KEY FINDINGS:

All respondents believed that there was a core body of knowledge on palliative care that physicians in their respective specialty areas should be trained in.

Respondents emphasized the importance of including palliative care in medical school and postgraduate training curricula in order to influence the practice patterns of new physicians.

Respondents did not favor the creation of an American Board of Medical Specialties palliative care specialty/subspecialty.

Several respondents believed that colleagues would support collaborative efforts to develop formal palliative care services not seen routinely today and/or use such services.

The report that follows summarizes key discussion points from the interviews.

Should Palliative Care be a Focus of Attention?

All of the participants in the survey believed that there was a core body of knowledge on palliative care - even if not fully defined yet - that physicians in their respective specialty areas should be trained in. None felt that current education and training was adequate and all believed that preparation of medical students and residents would be the key for improving the quality of end of life care that could be provided by physicians. Respondents felt that the earlier that medical students and residents were introduced to palliative care as a part of practice, the better.

Several responders expressed frustration that medical education focuses on "science" to the detriment of the development of "people" skills. Promoting a mindset where "death is not failure" and where "not knowing a solution" is not equated with a physician being ignorant were examples of the types of changes needed in medical education. One responder advocated for teaching students "how to keep up with change" in contrast to the current focus on mastering scientific knowledge that is frequently outdated before graduation.

Some responders were pessimistic about changing the practices of their peers in relation to palliative care. One physician described his colleagues as " technical hot dogs" who were not trained to communicate, had limited time for patients and families, and sought the thrill of the big procedure. However, several indicated that fostering a commitment to lifelong learning is essential for physicians and that continuing education programs and/or recertification requirements that address issues *including* palliative care practices could support desired growth. One responder observed that the importance of palliative care emerges as physicians in his field build their practices, e.g. after five years of relationship building with families. Having continuing education available enables physicians to improve patient care.

Participants in the interviews described a range of strategies used by their professional associations to assist physicians improve quality of life for patients with disabling and terminal illnesses. Four respondents reported that papers and journal articles that provide guidance were either already accessible or planned for publication in journals read by their respective members. Two indicated that the ethics committees of their associations addressed palliative care concerns. Three reported that resolutions and/or statements on palliative care had been issued and distributed to members, reflecting significant policy discussion on the part of members. One indicated that a national conference on palliative care had been conducted where recommendations for future actions were developed.

Several responders noted that palliative care issues are addressed in presentations at annual professional association meetings and regional chapter meetings. Efforts to incorporate palliative care within core competencies for licensing certification and recertification were underway in three specialty areas. Educational initiatives such as "palliative care fellowship programs" (2), training programs, and ongoing continuing education programs were also cited. While palliative care issues were reported to be addressed within some specialties' fellowship programs, their absence from others was bemoaned.

Three responders indicated that availability of funding for research that further defines problems and/or describes best practices (managing symptoms and psychological aspects of dying) would be critical for engaging physicians in palliative care in the future.

Who is Raising the Issue of Palliative Care?

“My colleagues don’t discuss this, and the text books don’t cover palliative care”, reported one interviewee. Another reflected that most physicians lose only occasional patients, and therefore palliative care is not a major focus in their practice or specialty area. And another reflected that the approach of hospital systems in his region causes many physicians to surrender their patients to hospitalists. This practice disrupts the continuity of care for patients, but may not be resisted by physicians as adamantly as one might expect.

Despite frustrations expressed, the responders were aware of a mix of people across specialties and disciplines that advocated and/or coordinated programs to better serve patients who are terminally ill and to improve the training of health care professionals in this area. Four responders indicated that academics were more likely to raise palliative care issues within their respective specialty areas than other physicians. One responder indicated that direct care providers were more likely to raise these issues. Nurse practitioners, psychologists and clergymen were also identified as key resources in this effort.

Perspectives on Future Opportunities for Practicing Palliative Medicine within Current Specialty Areas?

Five participants believed that there would be increased opportunities for doctors within their fields of specialization to work in the area of end of life care. Of these respondents, one reported that he was actively involved in recruiting such physicians and knew of several regional openings. Another predicted that there would be an increase in such opportunities for primary care specialties.

One responder believed there could be opportunities across the board if the research base for palliative care were increased. The availability of funds consistently drives building of departments and programs. Another respondent who felt there would be some but not significant opportunity, concurred that funding would influence interest. He added that early medical training and reimbursement would determine how many doctors would entertain directing their careers towards palliative care.

Two physicians were hopeful that in time there would be opportunity within their field; but they did not see significant interest or growth of opportunity in their fields. One physician thought opportunity would reflect the market and the individual. Given the “scientific bent” of students recruited to medical school, he was pessimistic about the number of people who would focus on palliative care.

Who will be with you when you die?

Four participants indicated that all physicians are responsible for palliative care and that there is no unique role for a palliative care physician. “Physicians should be able to preside over a good death for their patients.” One further indicated that palliative care should be a subject required in every residency program and that continued focus should be provided in primary care training. Another indicated that palliative care referrals were not so robust that one could support a practice in this area alone.

Four participants felt that *educating others* was an important role for physicians with palliative medicine expertise. Educators were believed needed in both academic and clinical settings. Developing educational materials for others was also identified as a piece of this role.

Other roles identified for physicians with palliative care training include c*onsulting to others* (3), *research* (2), *handling complicated cases* (1) and *leading programs* (1).

A Separate Specialty?

None of the individuals interviewed favored creating a distinct palliative care specialty/ subspecialty. Two responders indicated, however, that if palliative care were to evolve in this direction, they would foresee two benefits: more research on issues including pain management, grief management and other psychological concerns, and increased focus on education. Another believed that specialization might "increase the bar" for an individual physician. One responder indicated that he would find it necessary to be "certified" only if the specialty/subspecialty were recognized by the American Board of Medical Specialties.

Respondents raised several concerns regarding the development of a palliative care specialty/subspecialty which include: the further fragmentation of medicine; disruption of care provided through the physician already known to a patient; reinforcement of physicians' reticence to acknowledge death as a part of patient care by facilitating referrals of dying patients; the adequacy of the number of specialists who would be trained to respond to patients; and the attractiveness of such a specialty to future physicians.

Two responders emphasized the importance of having a) all practicing physicians have basic familiarity with palliative care and b) all physicians specializing in Internal Medicine have developed additional expertise. One physician suggested that establishing Palliative Care Centers of Excellence would be preferable to the creation of a new medical specialty. Since a hierarchy is needed to organize medicine, such centers could assume leadership in developing best practices and supporting education and practice. Another responder suggested that increasing standards for all physicians was preferable to encouraging referral of dying patients generally. And another felt palliative care resources would be better invested in developing community supports to assist physicians manage care for terminally ill patients and their families, and in building medical schools' palliative care programs rather than in seeking specialty status.

One responder noted that when HIV was "new and sexy" many young physicians entered this field. He felt many physician practices "went under" because the reimbursement did not match the acuity of the patients' illnesses. Today, changes in the management of HIV AIDS and the population most at risk (substance abusers) as well as reimbursement issues make him wonder who will provide this care in the future. He suggested that similar challenges might befall palliative care, where acuity and numbers as well as insufficient reimbursement may overwhelm physicians in such a specialty practice.

Collaborate with Others?

Six of the eight respondents believed that members of their specialty would be open to working with others to support the development of palliative care services not seen routinely today. Several recognized overlapping interest (management of pain, grief and loss, commodity) with other medical specialty areas and with other disciplines, such as nursing and the clergy. Combining forces was seen as both important and practical given diminishing resources in healthcare settings, e.g. availability of medical students. Several physicians indicated they already worked with interdisciplinary teams to collaborate on cases and saw other opportunities to expand collaborative efforts, e.g. introducing pain rounds in their hospitals.

Several participants believed that their colleagues would and do utilize palliative care programs for their patients where they exist. These services extend the supports one can offer families. One respondent felt that referral patterns among physicians should be examined, as it was suspected that some physicians would offload the more difficult, time-consuming cases. This was seen as bad practice from both professional and reimbursement perspectives. One respondent felt the colleagues in his specialty would need a more defined sense of what palliative care offers, i.e. services they do not already offer, before collaborating. Another felt that since colleagues did not yet buy into palliative care, it would be best to focus any efforts on training new physicians.

One respondent felt that his colleagues, who focus on invasive procedures, will be slow to focus on palliative care issues. He felt primary care physicians, nurses and clergymen were more likely to collaborate on the development of interdisciplinary services. Interestingly, he saw educating clergy on medical issues as a strategy to help support family exchanges with physicians.

A physician favoring coordination bemoaned the current practice of first isolating primary care physicians from cases when referrals are made to some specialists, and then having the patients "dumped" back when specialists see no chance to save the individual. Kept out of the loop, this physician reports that primary care providers are left to manage the patient's death without benefit of time to introduce and discuss palliative treatment with the patient, family and the specialist.

One respondent suggested that a consortium of societies could develop model legislation to fund services or address barriers to improve care and supports for terminally ill patients and their families.

Education Requirements and Standards of Practice

Several participants emphasized the importance of including palliative care within the core curriculum of medical school and postgraduate training programs. Several favored introducing competency testing. Only one responder indicated that her specialty had established educational requirements for residents and or practitioners specifically in palliative care. Two indicated their specialties had none in place and the remaining participants were unsure of their specialties' exact requirements.

None of the responders reported having "best practices" in palliative care established for their specialty. Several noted that journal articles, self-instruction manuals and some training opportunities were available. Existing resources were viewed as guidance from educational forums, not legal or medical standards for care. One physician identified the EPEC program as being as close to a best practice as is available today. He characterized EPEC as providing a foundation rather than advanced assistance to physicians. One responder is involved in a project to develop guidelines on resuscitation and end of life care. Another strongly advocated standard setting by residency review committees, and at national, local and hospital settings.

Two responders questioned the desirability of establishing standards of care in this area: If too prescriptive standards may not be useful for all populations (age, gender etc.) affected by an illness. If too dilute, what value are they? Also, concern was raised regarding physician and hospital/hospice liability if protocols are standardized. It was thought that "subpoena" protocols might inhibit pragmatic interventions that can be developed to respond to specific illnesses or patient need. One responder emphasized that standards should be appropriate for the settings care is provided in.

Several responders indicate that in the absence of standards, they look to others for training and insight. These include other physicians in their own or other specialties and nurse practitioners. One physician indicated he was more interested in best evidence that in consensus around protocols. One responder suggested that JHACHO integrate palliative care into its pain guidelines.

Challenges in improving care provided to patients with disabling and/or terminal illnesses in their current specialty areas

Participants in the research project were asked to identify challenges confronting members of their specialties in providing care to patients with serious medical conditions.

Reimbursement

Reimbursement was identified as a key factor affecting the practice of palliative medicine (4). Responders felt that reimbursement levels for palliative care should be higher, and that seed money might be needed to focus the attention of physicians on this arena of care.

From a practical perspective, physicians earn more money by doing procedures than by making house calls; and this affects how physicians allocate their time. Reimbursement needs to reflect the direction our health systems want care to take. Reimbursement systems should be designed to sustain professionals providing "desired" care, as well as assure access to other support services needed by patients.

Inconsistencies across payment systems were noted to further complicate the delivery of palliative care services. One respondent reported that Medicare would reimburse hospice services for a period of six months. His home state, Arizona, limited Medicaid reimbursement for hospice to 30 days. Such disparities affect the services that can be developed or accessed within a community.

Some important trends in procedure usage (including Pain Management) are not tracked by Medicare. Without such data, it is difficult to develop appropriate, cost effective approaches to care for patients, including those who have terminal illnesses.

Influencing Practice

Strategies suggested to influence change in physician practices related to palliative care include:

- Embed palliative care issues in the design of electronic medical records. It will be easier to change the process of reviewing care when introducing other system changes.

- Increase research documenting effective ways to manage symptoms in diseases/ populations addressed. It is to the advantage of a specialty to improve care.
- Reward expertise and excellence to get MD attention. May need carrot or whip to influence change. Try money.
- Educate the public on palliative care. With external pressure, consensus guidelines based on objective data may influence care provided, such as occurred with smoking.
- Design services for the patient. Advocacy groups should raise expectations.
- Psychiatric literature that can inform end of life care practices is limited. At least two responders felt that psychiatrists could play a larger role in supporting education of the physician workforce.

Attitudes

Providing high quality comprehensive care for patients with serious conditions involves influencing the current attitudes and consequent behavior of key groups: physicians, other professionals and the public. The following are some of the opinions of responders:

- Physicians are taught to cure others, not to help others confront the limits of care.
- Doctors need to be taught how to prepare for death and to examine who needs to be in control of the process.
- "Not knowing" is not acceptable in medical training. Training is not provided for handling uncertainty.
- The term END OF LIFE CARE artificially divides care physicians should be providing. Physicians palliate all the time; this is part of medical care. We shoot ourselves in the foot by such a dividing line.
- Nurses and others need information on palliative care. They may resist providing prescribed care for fear of being responsible for the death of a patient.
- The American public has unfulfillable expectations and rewards physicians who do more not less.
- Many physicians do not want to work in the area of palliative care. These physicians will let others take over their cases and absent themselves.
- Palliative care is a health issue, the "meat of medicine. It is not a nice dessert that should require outside money for support".

Physician Training

There is concern that physicians are not required to demonstrate skill in providing palliative care.

Several responders recommended that better training be provided to physicians and that professional associations initiate and/or continue to educate members in palliative care.

One respondent worried that younger physicians may lack the life experience that creates interest in palliative medicine. Training becomes central to assure that younger doctors view this care as part of mainstream medicine.

Community Resources

The availability of community resources was seen as critical to the provision of comprehensive palliative care services. For example, access to technical and non-technical home care resources will affect the need for referrals to hospitals and hospices. Expanding funding for services was seen as critical for the provision of good care.

E. Literature Review: Physician Workforce Issues Related to the Supply, Demand and Use of Palliative Care Physicians in the United States

Increasing concern regarding the care and support services that are available to patients diagnosed with terminal or chronically disabling conditions in the United States has stimulated debate on the feasibility of expanding palliative care services in hospital, hospice and community settings. Among the issues to be sorted through is the role that physicians will play in designing, delivering and/or coordinating such services for patients and for family members.

The literature review that follows provides a listing of references that explore key issues related to the delivery of palliative care services and to the palliative care physician workforce. Topics covered include: (1) Improving Care for People with Serious and Life Threatening Illness: An Overview; (2) Emerging Palliative Care Programs; (3) Education and Training for Physicians in Palliative Medicine; (4) Determining the Desirability of New Medical Specialties; (5) Barriers to the Provision of Palliative Care; and (6) Challenges in Delivering Palliative Care Services to Patients with HIV/AIDs. Bibliographic references will guide readers through a range of relevant issues, but they are not intended to be exhaustive. References with asterisks flag resources that were found to be particularly helpful in understanding specific issues.

Improving Care for People with Serious and Life Threatening Illness: An Overview

Palliative care focuses on prevention and relief of suffering throughout the final stages of life. The World Health Organization defines palliative care as the “active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of treatment. (World Health Organization, Internet)."

Assuring that people with serious and terminal illnesses in the United States receive medical interventions and support services that maximize their quality of life presents many challenges including the following: The U.S. population is aging. Health care and related support services are currently insufficient to respond the surge in people likely to require chronic or end of life care. The dying process experienced by most people has become more extended due to the increasingly chronic nature of illnesses that cause death. This in turn requires the provision of services over time. Significant financial resources will be required to develop and sustain the range of clinical and support services that will be needed in this area.

In addition, health professionals generally have had limited formal education on palliative care. Many physicians report low comfort in addressing end of life issues, including prognostication (Christakis & Iwashyna, 1998; Curtis, Wenrich, Carline, Shannon, Ambrozy, & Ramsey, 2001; IOM, 1997; The SUPPORT Principal Investigators, 1995). Health professionals will require ongoing palliative care education and training to deliver effective services responsive to unique patient needs, both clinical and cultural, as well to incorporate advances in disease and symptom management into their practices.

Research that informs clinical practice in multiple health care settings is critical to this process. A number of studies have indicated that terminally ill patients are under treated for pain (Benedetti & Nichols 2001; IOM 1997). Studies have also indicated that some patients prefer care that focuses on comfort yet receive aggressive or life prolonging treatment (IOM, 1997; Larson & Tobin2000).

With over half the deaths in America now occurring in hospitals, attention to the delivery of comprehensive palliative care services has broadened from its early focus on hospice care to now include focus on delivery of services in institutional settings. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) was a research study significant in establishing the current focus on end of life care in institutional settings. Conducted in 1995, the study was designed to examine a process intervention to improve end of life decision making for seriously ill patients. While the intervention tested was unsuccessful, the study caused others to question whether changes in larger health care systems rather than in specific interventions was what was needed to influence the care provided (Cassel, Ludden, & Moon, 2000).

In 1997, the Institute of Medicine published a report on care at the end of life, Approaching Death: Improving Care at the End of Life. This comprehensive report details clinical, legal, financial, ethical and political issues related to dying. The report also presented recommendations for improving end of life care. Funding for palliative research and program development from public and private sources have further facilitated the development and testing of initiatives designed to improve end of life care.

Bibliography

Benedetti, C., Dickerson, E.D., & Nichols, L.L. (2001). Medical education: A barrier to pain therapy and palliative care. Journal of Pain and Symptom Management, 21(5), 360-362.

Cassel, C.K., Ludden, J.M., & Moon, G.M. (2000). Perceptions of barriers to high-quality palliative care in hospitals. Health Affairs, 19(5), 166-172.

Christakis, N.A., & Iwashyna, T.J. (1998). Attitude and self-reported practice regarding prognostication in a national sample of internists. Archives of Internal Medicine, 158(23), 2389-2395.

Curtis, J.R., Wenrich, M.D., Carline, J.D., Shannon, S.E., Ambrozy, D.M., & Ramsey, P.G. (2001). Understanding physicians' skills at providing end-of-life care: Perspectives of patients, families, and health care workers. Journal of General Internal Medicine, 16, 41-49.

Emanuel, L.L., von Gunten, C. F., & Ferris, F.D., (2000). Gaps in end-of life care. Archives of Family Medicine, 9, 1176-1180.

* IOM (Institute of Medicine) (1997). Approaching death: Improving care at the end of life. Washington, DC: National Academy Press.

Last Acts Palliative Care Task Force (1997). Last acts: Precepts for palliative care. Available HTTP: http://www.lastacts.org:80/docs/profprecepts.pdf.

* Lynn, J., Arkes, H.R., Stevens, M., Cohn, F., Koenig, B., Fox, E., Dawson, N.V., Phillips, R.S., Hamel, M.B., & Tsevat, J. (2000). Rethinking fundamental assumptions: SUPPORT's implications for future reform. Journal of the American Geriatrics Society, 48, S214-S221.

Matesa, J. (2001). State initiatives in end-of-life care: How end-of-life care can be a positive issue for policy leaders (Issue 9). Kansas City, MO: Community-State Partnerships to Improve End of Life Care.

Steinhaser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L., & Tulsky, J.A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA, 284(19), 2476-2482.

* The SUPPORT Principal Investigators (1995). A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatment (SUPPORT). JAMA, 274(20), 1591-1598.

Wolfe, J., Grier, H.E., Klar, N., Levin, S.B., Ellenbogen, J.M., Salem-Schatz, S., Emanuel, E.J., & Weeks, J.C. (2000). Symptoms and suffering at the end of life in children with cancer. The New England Journal of Medicine, 342, 326-333.

World Health Organization (Internet). WHO definition of palliative care. Available HTTP: http://www.who.int/dsa/justpub/cpl.htm.

Emerging Palliative Care Programs

Palliative care has long been associated with care provided in hospice programs. Efforts to formalize palliative care services within hospitals and other institutional health care settings have increased in the past decade in order to improve the quality of services available.

The palliative care programs that have emerged vary in structure, but may include one or more of the following services: inpatient care, outpatient care, hospice, consultation services, bereavement counseling, volunteer programs, and caregiver/family support programs (Bruera et al., 1999; Hopper, 2001; Jordhoy et al., 2000; Kuebler & Bruera, 2000; Milbank Memorial Fund, 2000; Muir, Krammer, & von Gunten, 1999). Characteristics of hospital-based palliative care include: interdisciplinary team work, involvement of patients and families in care planning, collaboration across clinical and administrative boundaries, and provision of bereavement and other services for families and staff members (Cassel, 2000). The hospice model has similar foci to hospital-based palliative care, with emphasis on around-the-clock accessibility and interdisciplinary work (IOM, 1997). Funding for programs comes from one or more sources including: clinical revenue, foundation grants, philanthropic contributions, institutional support and endowments (Milbank Memorial Fund, 2000).

In addition to their focus on improving the quality of end of life care, several of these model programs were designed to influence broader health system concerns, e.g. the education and training of physicians (Muir et al.1999), access to services, physician practice patterns (Bruera et al., 1999), and communication strategies (e.g. use of the internet to provide medical support to underserved communities) (Kuebler & Bruera, 2000).

Physicians play critical roles in the emerging palliative care programs. These roles include dealing and negotiating with other physician colleagues, understanding the disease processes, and mentoring and managing house staff (Hopper, 2001).

Palliative care programs report encouraging results, including: increasing the proportion of patients who establish advance directives, fostering improvements in the assessment of patient needs, shift in death from hospital to palliative hospice and home care settings and trend toward greater patient satisfaction with the palliative care team (Bruera et al., 1999; Hopper, 2001; Jordhoy et al., 2000).

Bibliography

Bruera, E., Neumann, C.M., Gagnon, B., Brenneis, C., Kneisler, P., Selmser, P., & Hanson, J. (1999). Edmonton Regional Palliative Care Program: Impact on pattern of terminal cancer care. Canadian Medical Association Journal, 161(3), 290-293.

Cassel, C.K. (2000). Introduction. In Pioneer programs in palliative care: Nine case studies (pp.1-2). New York, NY: Milbank Memorial Fund.

Hopper, S.S. (2001). Building hospital palliative care programs: Lessons from the field. New York, NY: United Hospital Fund.

Jordhoy, M.S., Fayers, P., Saltnes, T., Elmqvist, M.A., Jannert, M., & Kaasa, S. (2000). A palliative-care intervention and death at home: A cluster randomized trial. Lancet, 356(9233), 888-893.

Kuebler, K.K., & Bruera, E. (2000). Interactive collaborative consultation model in end-of-life care. Journal of Pain and Symptom Management, 20(3), 202-205.

* Milbank Memorial Fund (2000). Pioneer programs in palliative care: Nine case studies. New York, NY: Author.

Muir, J.C., Krammer, L.M., & von Gunten, C.F. (1999). Training physicians in palliative care. Generations, 23(1), 91-95.

Pan, C.X., Morrison, R.S., Meier, D.E., Natale, D.K., Goldhirsch, S.L., Kralovec, P., & Cassel, C.K. (2001). How prevalent are hospital-based palliative care programs? Status report and future directions. Journal of Palliative Medicine, 4(3), 315-324.

Von Gunten, C., Camden, B., Neely, K.J., Franz, G., & Martinez, J. (1998). Prospective evaluation of referrals to a hospice/palliative medicine consultation services. Journal of Palliative Medicine, 1(1), 45-51.

Education & Training for Physicians in Palliative Medicine

The availability of trained health care professionals affects the quality of end of life care. Palliative care education and training programs are increasingly available to physicians through medical school, residency and fellowship programs, as well as through continuing education courses. In 1997, the Robert Wood Johnson Foundation and the Project on Death in America brought together academic leaders and developed recommendations to guide teaching in end-of-life care (Gelband, 2001). In 1998, the Accreditation Council on Graduate Medical Education (ACGME) made palliative care education a residency training program requirement in internal medicine.

Providing adequate education and training for U.S. physicians in palliative care remains a challenge as has been documented in studies conducted since the early 1990s. Few schools have provided a palliative care course and medical students have had little clinical exposure to palliative care. General medical textbooks present little information that would help doctors care for a dying patient. Medical students and physicians express low comfort levels in addressing these issues. (Benedetti, Dickerson & Nichols, 2001; Billings & Block, 1997; Carron, Lynn, & Keaney, 1999; Emanuel, von Gunten, & Ferris, 2000; Gelband, 2001; IOM, 1997; MacLeod, 2001; Oneschuk, Hanson & Bruera, 2000; Rabow, Hardie, Fair, & McPhee, 2000; Ury, Reznich, & Weber, 2000). It is interesting to note that the UK requires clinical rotations in palliative care and offers many elective rotations to undergraduate medical students. The U.S. and Canada do not require such mandatory rotations (Oneschuk, Hanson, & Bruera, 2000).

The literature identifies several barriers to developing educational programs in palliative care for new physicians. These include the extensive curricula already required in medical education and consequent time pressure, the absence of accepted norms in palliative care and standards for training programs, turf issues among departments, limited and decreasing funds for graduate medical education, the "red tape" and political issues in organizations, and the absence of trained leaders in palliative care (Billings, 2000; Gelband, 2001; IOM, 1997; Mount et al., 1994; Ury, Reznich, & Weber, 2000).

There has been a steady increase in the number of fellowships offered in palliative care across the country, though existing programs were reported to experience early problems with recruitment of good candidates and/or filling training slots. Case studies describing approaches taken to prepare physicians to deliver quality palliative care and in so doing influence lifelong practice patterns are now being documented (e.g., Fins & Nilsons, 2000; Turner & Lickiss, 1997). The availability of such models will support introduction of such programs in other settings. Other strategies to improve palliative care training for physicians include conducting needs assessments to support curriculum change and to address the needs of learners, and providing role models. (Meekin, Klein, Fleischman, & Fins, 2000; Ury, Reznich & Weber, 2000).

Bibliography

*Bain, J.W. (2001). State initiatives in end-of-life care: Education (Issue 10). Kansas City, MO: Midwest Bioethics Center.

Benedetti, C., Dickerson, E.D., & Nichols, L.L. (2001). Medical education: A barrier to pain therapy and palliative care. Journal of Pain and Symptom Management, 21(5), 360-362.

* Billings, J.A. (2000). Palliative medicine fellowship programs in the United States: Year 2000 survey. Journal of Palliative Medicine, 3(4), 391-396.

Billings, J.A., & Block, S. (1997). Palliative care in undergraduate medical education: Status report and future directions. JAMA, 278(9), 733-738.

Block, S.D., Bernier, G.M., Crawley, L.M., Farber, S., Kuhl, D., Nelson, W., O'Donnell, J., Sandy, L., & Ury, W. (1998). Incorporating palliative care into primary care education. Journal of General Internal Medicine, 13, 768-773.

Carron, A.T., Lynn, J., Keaney, P. (1999). End-of-life care in medical textbooks. Annals of Internal Medicine, 130(1), 82-86.

Emanuel, L.L., von Gunten, C.F., & Ferris, F.D. (1999). The education for physicians on end-of-life care (EPEC) curriculum. The Robert Wood Johnson Foundation.

Emanuel, L.L., von Gunten, C.F., & Ferris, F.D. (2000). Gaps in end-of-life care. Archives of Family Medicine, 9, 1176-1180.

Fins, J.J., & Nilson, E.G. (2000). An approach to educating residents about palliative care and clinical ethics. Academic Medicine, 75(6), 662-665.

* Gelband, H. (2001). Professional education in palliative and end of life care for physicians, nurses and social workers. In K. Foley & H. Gelband (Eds.), Improving palliative care for cancer (pp. 9:1-9:40). Washington, DC: National Academy Press.

Hilden, J.M., Emanuel, E.J., Fairclough, D.L., Link, M.P., Foley, K.M., Clarridge, B.C., Schnipper, L.E., & Mayer, R.J. (2001). Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology Survey. Journal of Clinical Oncology, 19(1), 205-212.

Hopper, S.S. (2001). Building hospital palliative care programs: Lessons from the field. New York, NY: United Hospital Fund.

IOM (Institute of Medicine) (1997). Approaching death: Improving care at the end of life. Washington, DC: National Academy Press.

Keogh, K., Jeffrey, D., & Flanagan, S. (1999). The palliative care education group for Gloucester shire (PEGG): An integrated model of multidisciplinary education in palliative care. European Journal of Cancer Care, 8, 44-47.

* LeGrand, S.B., Walsh, D., Nelson, K., & Zhukovsky, D.S. (2000). Development of a clinical fellowship program in palliative medicine. Journal of Pain and Symptom Management, 20(5), 345-352.

MacLeod, R.D. (2001). On reflection: Doctors learning to care for people who are dying. Social Science & Medicine, 52, 1719-1727.

MacLeod, R.D., & James, C.R. (1997). Improving the effectiveness of palliative care education. Palliative Medicine, 11, 375-380.

MacLeod, R.D., & Robertson, G. (1999). Teaching about living and dying: Medical undergraduate palliative care education in Wellington, New Zealand. Education for Health: Change in Learning & Practice, 12(2), 185-192.

Meekin, S.A., Klein, J.E., Fleishman, A.R., & Fins, J.J. (2000). Development of a palliative education assessment tool for medical student education. Academic Medicine, 75(10), 986-992.

Mount, B.M., Scott, J.F., Bruera, E., Cummings, I., Dudgeon, D., & MacDonald, N. (1994). Palliative care - A passing fad? Understanding and responding to the signs of the times. Journal of Palliative Care, 10(1), 5-7.

Oneschuk, D., Hanson, J., Bruera, E. (2000). An international survey of undergraduate medical education in palliative medicine. Journal of Pain and Symptom Management, 20(3), 174-179.

Rabow, M.W., Hardie, G.E., Fair, J.M., & McPhee, S.J. (2000). End-of-life care content in 50 textbooks from multiple specialties. JAMA, 283(6), 771-778.

Turner, K.S., & Lickiss, J.N. (1997). Postgraduate training in palliative medicine: The experience of the Sydney Institute of Palliative Medicine. Palliative Medicine, 11, 389-394.

* Ury, W.A., Reznich, C.B., & Weber, C.M. (2000). A needs assessment for a palliative care curriculum. Journal of Pain and Symptom Management, 20(6), 408-416.

Determining the Desirability of New Medical Specialties

Palliative medicine is a recognized medical specialty in countries including the United Kingdom, Ireland, Australia, and New Zealand (Carlton et.al., 2000; IOM,1997; Seely, Scott, & Mount, 1997). It is not yet clear whether palliative medicine will become a formally recognized medical specialty in the United States. While there are voices within the American medical community advocating for American Board of Medical Specialties certification for palliative medicine, others express caution or opposition to moving in this direction.

The existing literature identifies potential benefits and risks in creating any new medical specialty, not just palliative medicine. Potential benefits include: increasing recognition, power and validation of the new field (Burchardi, 2001; Doyle, 1994; IOM, 1997; Seely, Scott, & Mount, 1997); improving education and research in the field (Doyle, 1994; IOM, 1997; Seely, Scott, & Mount, 1997); attracting new recruits and leaders to the field (IOM, 1997; Seely, Scott, & Mount, 1997; Roy, 1994); and filling the gap of existing health care delivery systems (Rosenbaum, Friction & Okeson, 2001).

Those voicing caution raise concerns including: increased fragmentation of medical care resulting from the development of additional specialties (Council of Medical Specialty Societies, 1998; IOM, 1997; Lewy, 1977; Mount et al., 1994; Roy, 1994; Skolnick, 1992); need for general medical education to incorporate emerging issues (Kelly, 1999; Skolnick, 1992); need for more faculty resources and/or diverting resources from existing specialties (IOM, 1997); potential difficulties for practice and reimbursement in managed care environments where emphasis is on primary care practitioners (IOM, 1997); concern that physicians in other specialties may cede responsibilities for care and connection with patients (IOM, 1997; Librach, 1988; Roy, 1994; Skolnick, 1992); and escalation of health care costs (Council of Medical Specialty Societies, 1998).

Certification of Palliative Medicine

The American Board of Medical Specialties (ABMS) and the American Board of Internal Medicine (ABIM) have established specific criteria for the certification of new specialty or subspecialty areas. Medical specialties that have such certification typically focus on procedures and technology (e.g., radiology, surgical disciplines), specific populations (e.g., pediatrics, geriatrics), or particular organ systems (e.g., cardiology, gastroenterology) (Kelly, 1999).

Palliative Medicine currently meets several of the ABMS and ABIM criteria. For example, professional associations that focus on palliative medicine have been established, and professional journals targeted to physicians have been created that address clinical treatment, patient and caregiver support, professional support and other related issues. A growing number of medical schools have developed undergraduate, residency, and fellowship programs in palliative care to improve physicians' skills and knowledge.

Debate on the desirability of palliative medicine as a specialty/subspecialty continues around concerns including: the role of the palliative care specialist v, the role of other physicians in coordinating care for patients with serious and life threatening illness; the adequacy of reimbursement for palliative care services; and the acceptance of the field by other specialty areas.

Bibliography

American Board of Medical Specialties (2001). 2001 annual report & reference handbook. Evanston, IL: Author.

Burchardi, H. (2001). Specialty status for intensive care medicine? European Journal of Anaesthesiology, 18, 68-69.

Charlton, R., Field, S., Faull, C., Campbell, I., Harper, C., & Harper, L. (2000). The effect of the general practice registrar year on perceived skills in palliative care in the West Midlands. Medical Education, 34, 928-935.

* Council of Medical Specialty Societies (1998). The balance between generalism and specialism in American medicine: What is it? What should it be? Available HTTP: http://www/cmss.org/gen_spec_symposium.html

Doyle, D. (1994). Palliative medicine: A UK specialty. Journal of Palliative Care, 10(1), 8-9.

Field, D., & Addington-Hall, J. (1999). Extending specialist palliative care to all? Social Science & Medicine, 48, 1271-1280.

Francisco, G.E., Chae, J.C., & DeLisa, J.A. (1995). Physiatry as a primary care specialty. American Journal of Physical Medicine & Rehabilitation, 74(3), 186-193.

Hanson, L.C., Earp, J.A., Garrett, J., Menon, J., & Danis, M. (1999). Community physicians who provide terminal care. Archives of Internal Medicine, 159, 1133-1138.

Holman, G.H., & Smith, D.C. (1999). Board certification in palliative care for U.S. physicians. Journal of Pain and Symptom Management, 17(5), 309-310.

* IOM (Institute of Medicine) (1997). Approaching death: Improving care at the end of life. Washington, DC: National Academy Press.

* Kelly, M.A. (1999). The hospitalist: A new medical specialty? Annals of Internal Medicine, 130, 373-375.

Levy, M.A. (1988). Palliative care: Special and deserving of specialty status. Journal of Palliative Medicine, 4(1-2), 19-22.

Lewy, R.M. (1977). The emergence of the family practitioner: An historical analysis of a new specialty. The Journal of Medical Education, 52(11), 873-881.

* Librach, S.L. (1988). Defining palliative care as a specialty could do more harm than good! Journal of Palliative Care, 4(1/2), 23-24.

Mount, B.M., Scott, J.F., Bruera, E., Cummings, I., Dudgeon, D., & MacDonald, N. (1994). Palliative care - A passing fad? Understanding and responding to the signs of the times. Journal of Palliative Care, 10(1), 5-7.

Oneschuk, D. (1999). The evolution of palliative medicine education in Canada. European Journal of Palliative Care, 6(6), 198-202.

Rose, J.H., O'Toole, E.E., Dawson, N.V., Thomas, C., Connors, A.F., Wenger, N., Phillips, R.S., Hamel, M.B., Reding, D.T., Cohen, H.J., & Lynn, J. for the SUPPORT Investigators (2000). Generalists and oncologists show similar care practice and outcomes for hospitalized late-stage cancer patients. Medical Care, 38(11), 1103-1119.

Rosenbaum, R.S., Friction, J.R., & Okeson, J.P. (2001). Orafacian pain emerging as a dental specialty. Journal of the Massachusetts Dental Society, 49(4), 36-38.

Roy, D.J. (1994). Editorial: Against entropy in palliative care. Journal of Palliative Care, 10(1), 3-4.

* Seely, J.F., Scott, J.F., & Mount, B.M. (1997). The need for specialized training programs in palliative medicine. CMAJ, 157(10), 1395-1397.

Skolnick, A.A. (1992). Women's health specialty, other issues on agenda of "reframing" conference. JAMA, 268(14), 1813-1814.

Challenges in delivering palliative care to people with HIV/AIDS

According to the National Center for Health Statistics (1999), HIV-related deaths in 1997 were one of the top 10 causes of death in people aged 5-64. While studies show that the barriers to accessing health care experienced by HIV-AIDS patients are similar to those for other patients, there are unique issues associated with HIV/AIDS and the provision of palliative care.

Under treatment of Pain

While pain is one of the most common presenting problems among HIV/AIDS patients, doctors tend to underestimate and/or overlook pain as a symptom requiring clinical intervention (Breitbart et al., 1996; Larue, Fontaine, & Collearu, 1997; Oleske & Czarniecki, 1999). The estimated prevalence of pain among patients with HIV/AIDS ranges from 25% to 90% (Larue, Fontaine, & Collearu, 1997; Marcus, Kerns, Rosenfeld, & Breitbart, 2000). Despite the severe pain experienced by a number of HIV/AIDS patients, the majority of patients are under treated for pain; this under treatment of HIV/AIDS patients far exceeds the under medication of pain in cancer patients.

Women, patients with low socioeconomic status, and past or current injection drug users are reported to be particularly vulnerable to under treatment of pain (Breitbart et al., 1998; Larue, Fontaine, & Collearu, 1997; Marcus, Kerns, Rosenfeld, & Breitbart, 2000). Lack of appreciation of acute and chronic pain associated with HIV/AIDS was found to be one of the main limitations in providing appropriate palliative care for children who are diagnosed with this illness (Oleske & Czarniecki, 1999).

Population at Risk and Social Barriers

Unlike other chronic and terminal illnesses, HIV/AIDS mainly affects younger people. HIV/AIDS patients also tend to be socially marginalized and/or stigmatized. For example, HIV/AIDS patients are more likely to be racial minorities, gay men, and injection drug users. They tend not only to have difficulties accessing health care in general but also to experience discrimination in receiving health care (Breitbart, Kaim & Rosenfeld, 1999; Curtis & Patrick, 1997).

HIV/AIDS patients are more likely to have former and current substance abuse problems, which raise concerns for addiction to pain medicine by both patients and physicians (Breitbart et al., 1998; Breitbart, Kaim & Rosenfeld, 1999; Marcus, Kerns, Rosenfeld, & Breitbart, 2000).

Communication Between Physicians and Patients

While the importance of clear communication with patients to elicit their preferences for end-of-life care is recognized, less than half of AIDS patients discuss end-of-life care with their physicians. Black and Hispanic patients are less likely to have such conversations than non-Hispanic white patients (Curtis, Patrick, Caldwell, Greenlee, & Collier, 1999; Wenger et al., 2001). The desire to have such discussions crosses racial and ethnic groups, even if the discussions do not occur (Haas et al., 1993).

Studies indicate that the quality of physician/patient communication as well as longer and trusting relationships between physicians and patients promote end-of-life discussions are associated with higher satisfaction with care and increased clinician knowledge of patient preferences (Curtis & Patrick, 1997; Curtis, Patrick, Caldwell, & Collier, 2000; Wenger et al., 2001). Patients are more likely to have an advance directive after a physician discussion (Wenger et al., 2001). HIV-infected patients have diverse opinions about end-of-life decisions, and may voice different preferences depending on their medical condition.

Given the high incidence and under treatment of pain, it will be important to identify strategies to improve physician understanding and skill in assessing and managing pain for patients diagnosed with HIV/AIDS. This will require understanding barriers to the delivery of more effective pain management, e.g. potential impact of hospice or physician reimbursement rates on services rendered or the availability of clinical guidelines. As the populations at risk for HIV/AIDS is shifting to populations whom physicians communicate less well with, identifying training and system supports that encourage timely and clear discussion of patient care preferences will be important.

Bibliography

*Breitbart, W., Kaim, M., & Rosenfeld, B. (1999). Clinicians' perceptions of barriers to pain management in AIDS. Journal of Pain and Symptom Management, 18(3), 203-212.

Breitbart, W., McDonald, M.V., Rosenfeld, B., Passik, S.D., Hewitt, D., Thaler, H., & Portenoy, R.K. (1996). Pain in ambulatory AIDS patients I: Pain characteristics and medical correlates. Pain, 68(2-3), 315-322.

* Breitbart, W., Passik, S., McDonald, M.V., Rosenfeld, B., Smith, M., Kaim, M., & Funesti-Esch, J. (1998). Patient-related barriers to pain management in ambulatory AIDS patients. Pain, 76, 9-16.

Breitbart, W., Rosenfeld, B.D., Passik, S.D., McDonald, M.V., Thaler, H., & Portenoy, R.K. (1996). The under treatment of pain in ambulatory AIDS patients. Pain, 65(2-3), 243-249.

Butters, E., & Higginson, I. (1993). Palliative care for people with HIV/AIDS: Views of patients, caregivers and providers. AIDS Care, 5(1), 105-116.

Charlton, R., Field, S., Faull, C., Campbell, I., Harper, C., & Harper, L. (2000). The effect of the general practice register year on perceived skills in palliative care in the West Midlands. Medical Education, 34, 928-935.

* Curtis, J.R., & Patrick, D. L. (1997). Barriers to communication about end-of-life care in AIDS patients. Journal of General Internal Medicine, 12, 736-741.

Curtis, J.R., Patrick, D.L., Caldwell, E.S., & Collier, A.C. (2000). The attitudes of patients with advanced AIDS toward use of the medical futility rationale in decisions to forgo medical ventilation. Archives of Internal Medicine, 160, 1597-1601.

* Curtis, J.R., Patrick, D.L., Caldwell, E.S., & Collier, A.C. (2000). Why don't patients and physicians talk about end-of-life care? Archives of Internal Medicine, 160, 1690-1696.

* Curtis, J.R., Patrick, D.L., Caldwell, E., Greenlee, H., & Collier, A.C. (1999). The quality of patient-doctor communication about end-of-life care: A study of patients with advanced AIDS and their primary care clinicians. AIDS, 13(9), 1123-1131.

Downey, M. (1997). Developing palliative care services for patients with AIDS. European Journal of Palliative Care, 4(4), 121-123.

Goldstone, I., & Kuhl, D. (1995). Patterns of care in advanced HIV disease in a tertiary treatment center. AIDS Care, 7(1), S47-S56.

Haas, J.S., Weissman, J.S., Cleary, P.D., Goldberg, J., Gatsonis, C., Seage, G.R., Fowler, F.J., Massagli, M.P., Makadon, H.F., & Epstein, A.M. (1993). Discussion of preferences for life-sustaining care by persons with AIDS. Archives of Internal Medicine, 153(24), 1241-1248.

Kaldjian, L.C., Jekel, J.F., & Friedland, G. (1998). End-of-life decisions in HIV-positive patients: The role of spiritual beliefs. AIDS, 12, 103-107.

Larue, F., Fontaine, A., & Colleau, S.M. (1997). Underestimation and under treatment of pain in HIV disease: Multicentre study. British Journal of Medicine, 314(7073), 23-28.

Lebovits, A.H., Lefkowitz, M., McCarthy, D., Simon, R., Wilpon, H., Jung, R., & Fried, E. (1989). The prevalence and management of pain in patients with AIDS: A review of 134 cases. The Clinical Journal of Pain, 5, 245-248.

Marcus, K.S., Kerns, R.D., Rosenfeld, B., & Breitbart, W. (2000). HIV/AIDS-related pain as a chronic pain condition: Implications of a biopsychosocial model for comprehensive assessment and effective management. Pain Medicine, 1(3), 260-273.

McCormack, J.P., Li, R., Zarowny, D., & Singer, J. (1993). Inadequate treatment of pain in ambulatory HIV patients. The Clinical Journal of Pain, 9, 279-283.

National Center for Health Statistics (June 30, 1999). National vital statistics report. Hyattsville, MD: Author.

Oleske, J.M., & Czarniecki, L. (1999). Continuum of palliative care: Lessons from caring for children infected with HIV-1. The Lancet, 354, 1287-120.

Rosenfeld, B., Breitbart, W., McDonald, M.V., Passik, S.D., Thaler, H., & Portenoy, R.K. (1996). Pain in ambulatory AIDS patients II: Impact of pain on psychological functioning and quality of life. Pain, 68(2-3), 323-328.

Stajduhar, K.I., & Davies, B. (1998). Palliative care at home: Reflections on HIV/AIDS family care giving experiences. Journal of Palliative Care, 14(2), 14-22.

Vincent, I., Bugler, C., Fraval, J., Vilde, J-L., Leport, C., D'Herouville, D., Moulin, P., Jodelet, D., Mallet, D., & Salamagne, M.H. (2000). Modalities of palliative care in hospitalized patients with advanced AIDS. AIDS Care, 12(2), 211-219.

* Wenger, N.S., Kanouse, D.E., Collins, R.L., Liu, H., Schuster, M.A., Gifford, A.L., Bozzette, S.A., & Shapiro, M.F. (2001). End-of-life discussions and preferences among persons with HIV. JAMA, 285(22), 2880-2887.

Wilson, I.B. (1997). End-of-life care in HIV disease. Journal of General Internal Medicine, 12(12), 784-786.

Barriers to the Provision of Palliative Care

As awareness of the need for palliative care services has grown, so has recognition of significant systemic barriers to the development of such programs. Some of these challenges fall within topics raised within this bibliography, i.e., the education and training of physicians and other health professionals or the adaptation of services to meet needs of patients with specific illnesses, such as HIV/AIDS. Other significant barriers are discussed in the articles that follow. These include:

Assuring financial support for the development and delivery of services:

Medicare and Medicaid both provide reimbursement for palliative care services. However, the variations in reimbursement methodologies at federal and state levels result in disparate access to services for patients and families residing in different parts of the country. The services and time frames of coverage are regarded by some as unnecessarily restrictive and inhibiting of use of palliative care.

Private insurance and managed care companies also vary in their coverage and approval of palliative care services. Establishing more uniform and/or equitable access to palliative care services remains a challenge (Bain, 2000; Zerzan, Sterns, & Hanson, 2000).

Geographic variables affect the availability of services:

Rural v. urban areas may have different types of palliative care programs available for patients, such as hospice. The types of facilities located within an area, e.g. hospitals and nursing homes, also influences the services most likely to be available (Pietriesik & Mor, 1999; Zerzan, Sterns, & Hanson, 2000).

Public policies on control of drugs influence the ability of physicians and programs to address the needs of patients:

Laws and regulations intended to control illegal use of substances may have the unintended consequence of inhibiting prescription of drugs, such as opioids, when sound medical practice would support their use. Fear of investigation and prosecution, and strict monitoring of drug prescription patterns at the State level may negatively influence physician practice patterns with under treatment of patients as an undesired consequence. While there is a trend toward adoption of medical guidelines that help distinguish between illicit and appropriate medical use of drugs, there is still great disparity in regulations across the U.S. Some of the resulting confusions restrict the availability of appropriate medication to individuals or groups of patients with chronic and terminal illnesses (Joranson & Gilson, 1994; Metesa, 1999).

Research on palliative care interventions for different populations, such as terminally ill children, and diverse illnesses is also cited as key to respond to the unique needs of patients. (Wolfe et al., 2000).

Bibliography

Bain, J.W. (2000). State initiatives in end-of-life care: Facts and controversies about nursing home reimbursement (Issue 7). Kansas City, MO: Community-State Partnerships to Improve End of Life Care.

* Cassel, C.K., Ludden, J.M., & Moon, G.M. (2000). Perceptions of barriers to high-quality palliative care in hospitals. Health Affairs, 19(5), 166-172.

Fazeny, B., Muhm, M., Hauser, I., Wenzel, C., Mares, P., Berzlanovich, A., Hagmeister, H., & Marosi, C. (2000). Barriers in cancer pain management. Wiener Klinische Wochenschrift, 112(22), 978-981.

General Accounting Office (2000). Medicare: More beneficiaries use hospice: Many factors contribute to shorter periods of use. Washington, DC: Author.

Hilden J.M., Emanuel, E.J., Fairclough, D.L., Link, M.P., Foley, K.M., Clarridge, B.C., Schnipper, L.E., & Mayer, R. J. (2001). Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology Survey. Journal of Clinical Oncology, 19(1), 205-212.

Hoffmann, D.E., (1998). Pain management and palliative care in the era of managed care: Issues for health insurers. Journal of Law, Medicine & Ethics, 26(4), 267-289.

* IOM (Institute of Medicine) (1997). Approaching death: Improving care at the end of life. Washington, DC: National Academy Press.

Joranson, D.E., & Gilson, A.M. (1994). Controlled substances, medical practice, and the law. In H.I. Schwartz (Ed.), Psychiatric practice under fire: The influence of government, the media and special interests on somatic therapies (pp. 173-194). Washington, DC: American Psychiatric Press, Inc.

Joranson, D.E., & Gilson, A.M. (1998). Controlled substances and pain management: A new focus for state medical boards. Federation Bulletin, 85(2), 78-83.

Joranson, D.E., Gilson, A.M., Ryan, K.M., Maurer, M.A., Nischik, J.A., & Nelso, J.M. (2000). Achieving balance in federal and state pain policy: A guide to evaluation. Madison, WI: The Pain & Policy Studies Group at University of Wisconsin Comprehensive Cancer Center.

Karson, S.G., & Gillespie, K.B. (June, 2000). Will insurers help pay for end-of-life care? Business & Health, 21-26.

Larson, D.G., & Tobin, D.R. (2000). End-of-life conversations: Evolving practice and theory. JAMA, 284(12), 1573-1578.

Metesa, J. (1999). State initiatives in end-of-life care: Advances in state pain policy and medical practice (Issue 4). Kansas City, MO: Community-State Partnerships to Improve End of Life Care.

Mount, B.M., Scott, J.F., Bruera, E., Cummings, I., Dudgeon, D., & MacDonald, N. (1994). Palliative care - A passing fad? Understanding and responding to the signs of the times. Journal of Palliative Care, 10(1), 5-7.

Pain & Policy Studies Group (1998). Resource guide: Information about regulatory issues in pain management. Madison, WI: University of Wisconsin Comprehensive Cancer Center. http://www.medsch.wisc.edu/painpolicy/

Petrisek, A.C., & Mor, V. (1999). Hospice in nursing homes: A facility-level analysis of the distribution of hospice beneficiaries. The Gerontologist, 39(3), 279-290.

Rousseau, P. (1998). Palliative care in managed Medicare: Reasons for hope and for concern. Geriatrics, 53(11), 59-65.

Wolfe, J., Grier, H.E., Klar, N., Levin, S.B., Ellenbogen, J.M., Salem-Schatz, S., Emanuel, E.J., & Weeks, J.C. (2000). Symptoms and suffering at the end of life in children with cancer. The New England Journal of Medicine, 342, 326-333.

Zerzan, J., Sterns, S., & Hanson, L. (2000). Access to palliative care and hospice in nursing homes. JAMA, 284(19), 2489-2494.

Chapter 3: Findings of the Study

The "Study of the Supply, Demand and Use of Palliative Care Physicians" yielded a picture of the palliative care physician workforce and identified challenges and barriers confronted in the delivery of palliative care. Findings are drawn from analyses of national surveys of 1) palliative care physicians and 2) hospitals that provide or plan to provide formal palliative care programs; interviews with experts in palliative care, medical educators, and leaders of medical specialties that frequently care for patients with chronically disabling or life threatening illness; and a review of the palliative care literature. Findings are presented within the following categories: (1) The Palliative Care Physician Workforce; (2) Training and Education of Palliative Care Physicians; (3) A Profile of Hospitals Providing or Planning to Provide Formal Palliative Care Programs; (4) Development of a Formal Medical Subspecialty in Palliative Medicine; (5) Patients Receiving Palliative Care Services; (6) Key Non-Physician Personnel Providing Palliative Care; (7) Assessment of the Marketplace for Palliative Care Physicians; and (8) The Role of Public Education in Influencing the Delivery of Palliative Care Services.

(1) The Palliative Care Physician Workforce

- **Two distinct groups of physicians providing palliative care on a regular and focused basis emerged among the physicians surveyed: 1) a small group of physicians whose practices revolve significantly around the provision of palliative care and 2) physicians involved on a modest, part time basis.** Physicians included in the study are affiliated with professional organizations promoting palliative care, and are thought to address issues related to palliative care, including death and dying, more frequently than physicians in general.
- **Physicians committing 20+ hours weekly to palliative care constitute 25.9% of the population surveyed, but provide almost 70% of the total hours devoted to palliative care activities that were reported. Physicians working 9 or fewer hours weekly in the practice of palliative care constitute 53.2% of palliative care physicians surveyed, and provide 14% of the services.** Almost 60% of physicians in this latter group devote four or fewer hours to palliative care each week. The palliative care activities reported on include direct care, research, teaching and administration.
- **Thirty nine per cent of the physician respondents are members of the American Board of Hospice and Palliative Medicine (ABHPM), a national medical board that oversees the voluntary certification of physicians and the development of standards for training and practice in palliative medicine.** The palliative care practices and perspectives of this group of physicians differ from the non certified physicians. For example, ABHPM physicians commit a greater percentage of their practices to palliative care and are more likely to feel adequately prepared for this field than the non certified physicians. Almost 40% of ABHPM certified physicians worked 20 or more hours per week in palliative care as compared to 17.2% of the non certified physicians.

Approximately 35% of the ABHPM certified physicians worked 9 or fewer hours in palliative care as compared to 60.3% of the non certified physicians.

- **Palliative care physicians are primarily drawn from two medical specialties and three subspecialties.** These include Internal Medicine (42.2%), Family Practice (31.3%), Oncology (20.7%), Geriatrics (16.5%) and Pain Management (7.8)[*]**.** ABHPM certified physicians and physicians working 20+ hours in the field weekly are most likely to have backgrounds in Internal Medicine. Non-ABHPM certified physicians and physicians working 9 or fewer hours in the field are most likely to have backgrounds in Family Practice.
- **The majority of palliative care physicians would prefer to provide more palliative care.** Of the 1019 survey respondents spending *less than 100%* of their practice in palliative care, 62.5% (620 physicians) report that they would prefer to increase their time in this area. ABHPM certified physicians were most likely to report this preference (77%).
- **Directing patient care, conducting research, teaching, consulting, and participating in public education activities are roles most likely to be performed by ABHPM certified physicians and physicians committing 20 or more hours to palliative care each week**. Non ABHPM physicians and physicians working 9 or fewer hours weekly in palliative care are most likely to serve as medical directors of hospice programs. It should be noted, however, that serving as medical director of a hospice is a significant role for all physicians in all categories. The roles most frequently performed by palliative care physicians are 1. Medical Director of a Hospice and 2. Direct Patient Care.
- **More physicians practice palliative care in hospice settings than any other workplace site.** Hospices (87.3%)**,** hospitals (77.6%), physician offices (70.9%) and nursing homes (59.1%) are the principal sites where physicians report practicing palliative care. However, the majority of physicians spend 9 or fewer hours per week in the practice of palliative medicine in every setting.
- **Specialists in Oncology, Internal Medicine and Family Practice make the most frequent referrals to palliative care physicians.** ABHPM certified physicians receive more frequent palliative care referrals than non ABHPM certified physicians, as do physicians working 20 or more hours weekly in palliative care as compared to palliative care physicians working fewer hours.

(2) Training and Education of Palliative Care Physicians

- **There is general agreement that all physicians should have background and skills enabling them to provide quality care to patients with serious and life threatening medical conditions. Improving the quality of training and education on palliative care for ALL PHYSICIANS is the workforce strategy most frequently identified by physician and hospital respondents to promote more effective palliative care in the United States in the long term.**

---

[*] Respondents can indicate background in more than one medical specialty area.

Medical educators and leaders of other specialties emphasize the importance of integrating palliative care training within the core curriculum of medical schools and postgraduate training to influence practice patterns of new physicians. This training would address attitudes and approaches to care in addition to skill development. The clinical years are seen as particularly important for influencing future practice. Experiential learning, lectures, case studies, rounds and supervised practice are the learning formats that physician respondents believe best prepare physicians to practice palliative medicine.

- **A core body of knowledge is recognized to exist in palliative medicine.** Medical educators and leaders of specialties interviewed concur that there is a distinct body of knowledge on palliative care that physicians should be trained in. Physician respondents identified pain management; communications with patients, family and other health professionals; the process of dying; and symptom management as essential topics to be covered in palliative medicine education and training programs.
- **Medical educators report "unusual support" for including palliative care in medical school curricula from medical school faculties.** Resistance to programs, where it exists, is attributed to the challenge of integrating any new material into a medical school's core curricula and assuring necessary funding for preparation of new materials and/or courses.
- **While 70.5% of physicians certified by the American Board of Hospice and Palliative Medicine felt their palliative care training adequately prepared them for palliative care practice, only 37.9% of non certified physicians felt adequately prepared. Physicians working 20+ hours weekly in palliative care were more likely to feel that their palliative care training adequately prepared (54.9%) them than physicians working fewer hours. Respondents working 9 or fewer hours in the field were least likely to feel previous training prepared them for palliative care practice (34.5%).**

  Over twenty per cent of the physician respondents reported that they had not completed any formal education or training program in palliative care. These respondents are more likely to be non ABHPM certified physicians and physicians working 0-9 hours weekly in palliative care. While this is a new field and some of these physicians may have had few training options available when they began working in palliative care, it will be important to assure that physicians have the expertise to perform roles and responsibilities they assume in this area.

  ABHPM certified physicians across the five specialties from which most respondents were drawn reported being significantly more prepared in palliative care than non certified respondents in their respective fields. ABHPM certification thus would seem to provide a valuable process for developing expertise in palliative medicine.
- **An increasing range of education and training opportunities are available to physicians interested in palliative care. The Education for Physicians on End of Life Care (EPEC) course and trainer training have proved to be significant resources for physicians across age groups and across the specialties from which palliative care physicians are most frequently drawn.**

Short courses are the program type most frequently cited by physicians in describing training completed (49.9%). Physicians working 20 or more hours in palliative care weekly were most likely to participate in fellowship programs, suggesting that the fellowships are preparing physicians who will make broader commitments to palliative care within their practices.

(3) A Profile of Hospitals Providing or Planning to Provide Palliative Care Services

- **Hospitals anticipate changes in their formal palliative care services including: increases in the number of patients served (76.2%), expansion of the type of services offered (66.8%) and/or redesign of services (48.4%) over the next 18 months.** Only 1.2% of respondents anticipate that palliative care services would be reduced. This suggests strong continued commitment to the provision of these services by respondents.
- **Hospitals that provide or plan to provide palliative care services are more likely to be larger hospitals. Nearly three quarters of the respondents are non government, not for profit hospitals. Over 70% of hospital respondents contract with hospice organizations within their communities.** Hospital respondents are twice as likely as hospitals responding to a national survey conducted by the AHA in 1999 to have 200 or more beds (57.9% to 25.1%)[2]. Non government not for profits and Federal government hospitals are over-represented among study respondents in comparison to the AHA hospitals. Respondents are more likely than AHA hospitals to provide hospice, pain management and end of life services.
- **Close to 70% of the hospital respondents report that at least one physician working in their formal palliative care programs is ABHPM certified. Most hospitals report a small number of physicians working in their formal palliative care programs.** The majority of respondents currently utilize one or two physicians to provide palliative care in their formal palliative care programs. Over 10% of the hospital respondents report 10 or more physicians providing palliative care in their programs.
- **Hospitals prefer recruiting physicians with backgrounds in Internal Medicine, Pain Management, Oncology /Hematology, Geriatrics and Family Practice when recruiting for their palliative care programs.** Almost half of the respondents were unsure of their future recruitment plans. Of the hospitals (25%) anticipating recruiting physicians, almost three quarters reported that they would hire one physician.
- **Completion of EPEC courses, ABHPM certification and completion of fellowship programs addressing palliative care are the education and training backgrounds required or preferred in candidates.**
- **Rural hospitals report challenges in establishing palliative care programs that they attribute to low reimbursement levels and low patient volumes.**

---

[2] The AHA Annual Survey Database (FY 1999), Health Forum, LLC

(4) Development of a Formal Medical Subspecialty in Palliative Medicine

- **The majority of palliative care physician respondents and hospital respondents favor the development of a formal American Board of Medical Specialties (ABMS) subspecialty in palliative medicine.** Over half the physician respondents (54.5%) favor a formal subspecialty in palliative medicine. ABHPM certified physicians are much more likely to favor an ABMS subspecialty than non ABHPM certified respondents (73.8% to 39.1%). Physicians working more hours in the field are also more likely to favor a formal subspecialty (physicians working 20+ hours, 74.2%, physicians working 10-19 hours, 56.3%, physicians working 0-9 hours, 44.4%). Hospitals are also strong in their support, with 67.3% favoring the development of a formal medical subspecialty.
- **Leaders of Other Specialties oppose the development of a formal palliative care specialty.** While physicians interviewed on behalf of specialties that frequently care for patients with chronically disabling and terminal illness concur that physicians should be trained in palliative care, none favor establishing a distinct subspecialty in palliative medicine.

(5) Patients Receiving Palliative Care Services

- **Cancer is the most common diagnosis of patients who receive palliative care services as reported by physician respondents (91.7%) and hospital respondents (88%). COPD is the second most common diagnosis reported by physicians (54.4%)and hospitals (56.2%). CHF is the third most common diagnosis reported by the physicians (53.6%) and hospitals (56.2%).** Patients diagnosed with these three diseases receive the majority of palliative care services currently provided within physician practices and formal hospital palliative care programs.
- **Prognosis and life expectancy are the factors most frequently identified by hospitals as determining patient eligibility for palliative care programs.**
- **Few patients diagnosed with HIV/AIDS receive care within palliative care physician practices or formal palliative care hospital programs.** Less than 5% of palliative care physicians report HIV/AIDS as a common diagnosis among their patients receiving palliative care. Forty percent of the physicians have no HIV/AIDS patients in their palliative care practice while over half indicate that patients with HIV/AIDS constitute 5% of the practices. Only 12.4% of hospitals surveyed commonly treat HIV/AIDS patients within formal palliative care services. Close to half the hospitals did not have HIV/AIDS patients in these programs.
- **Addressing under treatment of pain and improving communication between patients and physicians are key challenges in providing palliative care to individuals diagnosed with HIV/AIDS.** HIV/AIDS patients of low socioeconomic status, women, children and past or current injection drug users with HIV/AIDS are reported to be particularly vulnerable to under treatment of pain. As the population at risk for this disease shifts to populations whom physicians may communicate less well with, e.g. people with drug and alcohol dependencies, identifying training and system supports that facilitate discussion of patient preferences and needs is important.

(6) Key Non-Physician Personnel Providing Palliative Care

- **RNs, social workers and chaplains are the non-physician personnel who work most routinely with physicians within their palliative care practices, and who work most frequently as part of core teams of personnel providing services in formal hospital palliative care programs.**

(7) Assessment of the Marketplace for Palliative Care Physicians

- **Physicians expect that their palliative care practices will grow.** Almost 80% of ALL respondents anticipate that their palliative practices will "grow/grow significantly" over the next three years. Only 2% expect that their palliative care practices will decrease. ABHPM physicians are more likely to anticipate "significant growth" in their palliative care practices than non ABHPM respondents. Physicians working 20 or more hours per week in palliative care are almost four times as likely as physicians working 0-9 hours weekly to anticipate "significant growth" in their practices.
- **A majority of hospitals (53.7%) perceive the supply of physicians with training in palliative care to be insufficient to meet the available jobs in their communities over the next 3 years.**
- **Over half of ALL respondents do not regard the supply of palliative care physicians to be sufficient to meet the needs of patients and families for services.** Physicians making broader commitments in training and time to the field of palliative care see greater insufficiencies in the supply of physicians available to meet the needs of patients and their families than other physicians. ABHPM physicians (64.2%) were more likely to see the supply as insufficient than non ABHPM physicians (47.8%). Physicians working 20 or more hours weekly in the field (71.4%) were much more likely to report the supply insufficient than physicians working 0-9 hours weekly in palliative care (47.2%). The scope of the practices of these physicians may provide different insights into unmet needs.
- **Physicians generally perceive current opportunity in palliative care as limited. Physicians making broader commitments to the field in training and time are more likely to report current opportunities in palliative care in their communities.** ABHPM certified physicians (40.3%) report more current opportunities (many/some) for palliative care practice than do non certified physician respondents (30.5%). Physicians committing 20 or more hours per week in palliative care (46.9 %) perceive more opportunities (many/some) as compared to physicians committing 0-9 hours per week (26.2%). Non ABHPM certified physicians (19%) are more likely to report no opportunities than ABHPM certified physicians (13.2%).
- **Medical educators and leaders of other specialties are divided in their perceptions of opportunities for physicians interested in palliative medicine.** The availability of funding, public demand and the existence of a research base were among the factors cited as influencing future opportunities.
- **Expanding and improving financing for palliative care services are regarded by physicians and by hospitals as key to delivering this care.** Respondents to the

physician and hospital surveys, medical educators and leaders of other specialties all cited reimbursement for physician services as a powerful factor in assuring that a sufficient supply of doctors will be available to meet the needs of patients and families. Funding of services by Medicare, Medicaid and other insurers, e.g. for medication and pain management, are described as currently inadequate. The availability of funding is a crucial factor in winning institutional support from hospitals for the development and operation of programs and for sustaining a sufficient supply of physicians in the provision of palliative care.

(8) The Role of Public Education in Influencing the Delivery of Palliative Care Services

- **Public education is seen as a means to increase demand for palliative care and, in so doing, to influence physician, hospital and other provider practices.** Physician and hospital respondents, medical educators and leaders in other specialties identify increasing public education in palliative care as a very important strategy to promote more effective palliative care across the U.S. "An informed public will be the most powerful force to change end of life care," noted one physician. Respondents' comments stress the importance of public debate on care for the terminally ill.

- **Physicians spend limited time on public education within their palliative care practices.** Physicians working 20 or more hours weekly in palliative care were almost 5 times as likely to perform public education roles all the time or frequently than physicians working 0-9 hours weekly in the field. ABHPM physicians (16.5%)were similarly more likely to perform public education roles than non ABHPM physicians (9.5%).

Chapter 4: Discussion of Findings

The following discussion of findings addresses issues including: (1) The Palliative Care Physician Workforce: Profile, Practice and Preparation; (2) Hospitals Providing or Planning to Provide Palliative Care Programs; (3) Patients Accessing Palliative Care Services; (4) The Marketplace for Physicians Providing Palliative Care; (5) Debate on the Desirability of an American Board of Medical Specialties Subspecialty in Palliative Care; (6) The Value of Educating the Public on Palliative Care; and (7) The Palliative Care Team.

(1) The Palliative Care Physician Workforce: Profile, Practice and Preparation

All physicians will care for patients within their practices each year who are seriously ill, including some patients who are dying. The physicians targeted in the study's survey were thought to address care of chronically disabling conditions and death and dying more frequently than physicians in general as a result of their affiliation with one or more palliative care professional organizations.

The survey documented that there is great similarity in background among physician respondents. They are primarily in mid career, white and male, though women are more represented among ABHPM certified physicians and physicians working 20 hours a week than their distribution among physicians nationally would suggest. Palliative care physician distribution across the country is consistent with physicians nationally, but they are more likely to be graduates of U.S. medical school programs and to be U.S. citizens than physicians nationally.

That said, significant differences among palliative care physicians exist in terms of their patterns of practice. These differences include the amount of time committed to palliative care, the perceptions held regarding sufficiency of services to meet patient and family need, and the roles assumed within the field. For example, physicians working 20 or more hours each week constitute 25% of the physicians responding to the CHWS survey, while providing 70% of all services reported. Physicians working 9 or fewer hours per week constitute 53% of the respondents and provide 14% of services reported. Physicians committing 20 or more hours weekly to palliative care practice are the most likely to perceive need for palliative care services by patients and families, which may be a consequence of their time commitment in this area. They also are more likely to teach, conduct research, provide direct patient care, and consult to other physicians and health professionals than colleagues committing fewer hours to palliative care each week.

It appears then that two general tracks exist among physicians currently identified with the field: In one, palliative care defines major components of a physician's practice. In the second, palliative care is an important commitment, but does not define a physician's broader practice. This suggests that future preparation of physicians in palliative medicine will not be uniform but will need to be tiered in focus: it will need to provide understanding and skill development appropriate for those physicians who only occasionally address the death of patients; for those working on a modest, part time basis and likely to serve a limited program population; and for those concentrating their medical practice in this area and working in one or more worksites and/or programs. It further suggests that the qualifications and performance standards for physicians in specific roles need to be clearly articulated to assure that the level of expertise required for tasks can be met by incumbents and job candidates.

Training and Education

Training ALL PHYSICIANS in palliative care is the workforce strategy most frequently cited by hospital and physician survey respondents to improve the quality of palliative care in the U.S. There is general agreement that a core body of knowledge in palliative medicine exists and that the palliative care approach should be incorporated into training provided to new and to mid career physicians. While efforts are underway to build palliative care into medical school curricula and professional association programs, palliative care issues are not yet fully integrated within educational offerings.

Current palliative care physicians have relied on a range of educational and training programs to prepare them for practice in the field. These include short courses, fellowship programs, residency rotations and medical electives. Notably, over one third of all palliative care physicians surveyed completed the EPEC course, and over one fifth of respondents completed the EPEC trainer course suggesting that many are sharing this information within their communities. EPEC offerings can be seen to play a very important role in providing core information to physicians.

ABHPM has provided an additional opportunity for palliative care physicians to demonstrate expertise in the field through voluntary board certification in palliative medicine. Physicians with ABHPM certification report feeling more adequately prepared for the practice of palliative care than non ABHPM physicians surveyed from the same specialty areas. This suggests that the process of becoming certified does influence physician preparedness.

While the majority of physicians surveyed completed some type of formal training, one fifth of palliative care physicians completed no formal training in palliative medicine. Some of these physicians may have learned “on the job” and /or entered the field before courses were more generally available. However, their lack of training is a cause for some concern. Establishing professional performance standards within different care settings is one strategy to assure that doctors have skills and expertise consistent with best practices within the field.

Medical school educators describe progress and support for introducing palliative care education into undergraduate and post graduate medical education to assure that new physicians are exposed to approaches and skill building in palliative medicine. The need to establish and/or utilize clinical sites and role modeling was further emphasized as critical to establish desired practice patterns early in doctors’ careers. Early exposure was also thought to influence consideration of long term commitments to this field. Educators express some frustration with limited communication across campuses that could promote sharing of experiences on curricula changes and teaching approaches. Outcome evaluations for new palliative care training initiatives and performance standards for new physicians are needed and in a small sample of institutions these are being formulated.

Medical specialty professional associations report that training in palliative care targeted to mid career physicians are increasingly available or planned, but they also are not regarded as meeting the educational needs of mid career physicians. Leaders of several professional associations and medical educators cite the desirability of incorporating questions on palliative care into recertification exams to assure demonstration of critical skills and/or knowledge. Developing strategies to strengthen mid career physician expertise in this area, which will require changing practice patterns and confronting physician discomfort with death, remains a major challenge.

Palliative care physicians are primarily drawn from two medical specialties: Internal Medicine and Family Practice. Many are also drawn from three subspecialties, Oncology, Geriatrics and Pain Management. Recognizing that development of expertise in palliative care is needed across medical specialties, assuring that education and training is available to physicians in the specialty areas most likely to attract physicians to the field is a priority.

(2) Hospitals Providing or Planning to Provide Palliative Care Services

Efforts to formalize hospital based palliative care services have increased in the past two decades in order to improve the quality of services available to patients and families. While the design and array of services offered vary, it appears that hospitals offering such formal palliative care programs remain very committed to them: hospitals surveyed report that they will be serving more patients, expanding the services offered, and/or redesigning current programs. Only 2% of the respondents will reduce services.

Survey findings suggest that formal services are most frequently found in larger hospitals and in nongovernmental not for profit hospitals. Federal government hospitals are also highly likely to have programs in place, reflecting the Veterans Administration Hospitals commitment to palliative care across the country. Since the profile of the survey respondents does not mirror AHA hospitals nationally in terms of facility size or range of hospital categories, it would seem that there are extensive opportunities for the introduction of such services in many hospitals across the country. This assumes that research on the impact of such programs can demonstrate that palliative programs add value to the quality of patient care, improves consumer perceptions of care provided and that financing makes such programs feasible. Rural hospitals responding to the survey were vocal in reporting frustrations and challenges in attempting to establish formal programs due to hospital size and geography. This suggests that different models and/or financing strategies are needed to assure the availability of palliative care services in non-urban areas. Finally, most hospital services currently focus on meeting the needs of patients who are dying. The opportunity to demonstrate how palliative care services can benefit patients with serious illness throughout the course of their illness will also effect the design of services hospitals ultimately implement in response to needs in their communities.

Hospitals value physicians with demonstrated expertise in palliative care within their programs. While the majority of hospitals currently report a small number of physicians working within their programs, almost 70 % report that at least one of these physicians is ABHPM certified. Physicians most likely to be recruited for their programs include specialists in Internal Medicine, Pain Management, Oncology, Geriatrics and Family Practice, and physicians who have completed educational programs such as fellowships in palliative care. The value hospitals place on “credentials” suggests that physicians recruited for hospital programs will be from that smaller pool of physicians who have already developed expertise in palliative care and may be more likely to commit larger portions of their practice to palliative medicine.

Hospitals offering formal services appear to be growing in number, and thus will be a potential practice site for increasing numbers of physicians. Hospice, however, remains the practice site most physicians report working in. Comparing the use of physicians in these workplaces will be important to inform physician training in palliative medicine. Hospitals report that the availability of financing for new initiatives and on-going operations is key to capturing institutional support for their efforts. Financing will therefore be a significant determinant in the extent of growth of such programs in hospitals.

(3) Patients Accessing Palliative Care Services

Disparities exist among patients diagnosed with terminal illnesses regarding access to palliative care services. Formal services are most likely to be provided to patients with a small number of diagnoses. These diagnoses include Cancer, Chronic Obstructive Pulmonary Diseases (COPD), and Congestive Heart Failure (CHF). While patient access to these services reflects physicians' current understanding of the progression of these illnesses and their consequent ability to predict a time frame for death, it also reflects regulatory practices that tie reimbursement for palliative care to life expectancy. To the extent that palliative care comes to be understood as including services provided over the duration of a life threatening illness and also appropriate for the treatment of care for chronic conditions, the range of diagnoses commonly treated will expand.

The physician culture in this country focuses on saving lives. Physician discomfort with confronting the death of patients and /or breaking bad news to patients and family members further impacts the options communicated to patients with life threatening illnesses. Influencing practice patterns of physicians is an important strategy to assure that all patients and families are permitted timely consideration of curative and/or palliative approaches to treatment.

Income, citizenship and geography further significantly influence which patients will be able to consider accessing existing palliative care services. For example, Medicare, a national program serving all persons 65 years of age and older and people with disabilities, serves 85% of the people who die annually. Most Medicare services cover acute episodes of treatment. Medicaid is an income eligible program jointly funded by federal and state funds that will typically cover support services, including long term care services, not covered by Medicare. Medicaid services vary across the country in terms of the eligibility, scope and duration of services covered. In states where service coverage of essential support services is very limited, individual patients may be precluded from selecting palliative care treatment options available to them under Medicare because they cannot access these necessary service supports. Additionally, some groups, including the uninsured and immigrants, may be excluded from accessing any palliative care services because of their incomes, lack of health coverage and /or citizenship status.

Finally, some groups face particular challenges in accessing palliative care services. These include minorities, women, individuals with histories of chemical dependencies, immigrants and children. Health care systems frequently do not effectively address the needs of individuals with diverse racial and ethnic heritages. The approach to services for children and their families and the clinical research base is distinct from palliative care services generally which tend to focus on older adults. While the number of children needing palliative care services is regarded by many in the field as "small", pediatricians working in this area voice the need to establish best practices for this care.

Patients Diagnosed With HIV/AIDS

Few patients diagnosed with HIV/AIDS receive care within physicians' palliative care practices or within formal palliative care hospital programs. Less than 5% of the physicians report HIV/AIDS as a common diagnosis in their practices, while 40% have no patients with this diagnosis in their practices. Similarly, one in ten hospitals report commonly having HIV/AIDS patients in their programs while close to half have no HIV/AIDS patients in formal palliative care programs. HIV/AIDS patients may be receiving palliative care from other physicians, hospital programs, or other service systems, but they are not utilizing the formal services studied in significant numbers.

HIV/AIDS is no longer regarded as a "terminal" diagnosis for patients. The literature suggests that HIV/AIDS patients are typically younger than people receiving formal palliative care services. Many are from population groups which experience difficulty accessing healthcare generally and which present particular challenges in the delivery of palliative care. For example, HIV/AIDS patients are more under-treated for pain than cancer patients. Those HIV/AIDS patients with histories of substance abuse may be further discriminated against in receiving pain medication due to concerns regarding past or present dependencies. Many HIV/AIDS patients may have added problems in communicating with physicians due to histories of poverty, ethnic and cultural backgrounds, or because they are children.

The literature suggests that patients with HIV/AIDS would like to discuss choices around death and dying with their doctors, but that at least half do not. Blacks and non white Hispanics are less likely to have these conversations. Assuring that doctors and/or teams of health professionals treating these patients have demonstrated skills in facilitating communication and in establishing trust and understanding of unique individual needs is particularly needed to address the needs of people with this illness.

Among the leaders of specialties frequently caring for patients with chronically disabling and terminal illness were physicians who treat patients with HIV/AIDS. These physicians reported that many doctors working with HIV/AIDS patients developed strong palliative care skills "on the job". They also comment that newer physicians cannot rely on gaining skills to assist patients who are confronting end of life issues in this way alone. With improvements in treatment and prognosis, the new physicians will not be exposed to as many HIV/AIDS patients at end of life as was previously the case. Investigating ways to draw on emerging palliative care services as resources when training new physicians or treating patients was thought to be desirable.

(4) The Marketplace for Physicians Providing Palliative Care

There are mixed findings in assessing the marketplace for physicians providing palliative care based on the surveys conducted with palliative care physicians, hospitals currently providing or planning to provide formal services, interviews with medical educators and other leaders of medical specialties that frequently care for patients with chronically disabling and life threatening illness; and review of current literature on the field. Almost 80% of all physician respondents perceive that their palliative care practices will grow in the next 3 years, with only 2% projecting a decrease. Those physicians with ABHPM certification and working 20 + hours, were more likely to project significant growth. Over 60% of the physicians who do not currently work full time in palliative care practice indicate that they would prefer to provide more palliative care. Hospitals providing these services, an important emerging worksite for palliative care physicians, also appear to be committed to their palliative care programs. Hospitals project increases in services that will require their recruiting some additional physicians, and are most likely to recruit physicians credentialed in the field. As discussed earlier, since the profile of the survey respondents does not mirror AHA hospitals nationally in terms of facility size or range of hospital categories, it would seem that there are extensive opportunities for the introduction of such services in many hospitals across the country. Study findings further suggest that the existing need for physicians and palliative care services by patients and families exceeds the availability of physicians to deliver services.

That said, physicians and hospitals express concern that current reimbursement levels and funding are inadequate to recruit or sustain physicians in practice, as well as to fund the educational initiatives essential to assure long term change. Today only one tenth of physicians derive their full income from palliative care, with a subset of physicians volunteering their services. The vast majority of physicians derive the major portions of their professional income from other sources.

Hospitals report that predictable and adequate funding is essential to seed and operate programs and to develop the institutional support required to conceptualize services and/or adapt the delivery system to better serve patients and families. *In fact*, a *national approach to funding palliative care services was thought by many to be required to assure access to affordable medication and care provided by physicians and other health professionals across the continuum of health care settings.* Availability of funds consistently drives the development of research, departments and programs. Reimbursement is a means to incentivize desired changes in health delivery systems, but is currently experienced as a restraint in the area of palliative medicine.

Other variables that will influence the ability of physicians to practice in this area include health care policies that determine the range of health and support services covered; the criteria for patient eligibility; development of standards in palliative medicine for hospitals and hospice programs; and the availability of philanthropic support for research and program development.

(5) Debate on the Desirability of an American Board of Medical Specialties (ABMS) Subspecialty in Palliative Medicine

One of the questions posed in framing the palliative care physician workforce study was whether there is need and support for a formal ABMS medical subspecialty in palliative medicine. The survey findings demonstrate that there is significant support for a formal medical subspecialty from U.S. physicians currently working in this field who are affiliated with professional associations that address hospice and palliative medicine issues. This support is greatest among those physicians who already demonstrate strong commitment to the field by becoming voluntarily certified through ABHPM and /or by committing 20 or more hours to palliative care practice each week.

It is important to emphasize that physicians surveyed felt that improving the quality of training and education in palliative care for ALL physicians was the top workforce strategy identified to promote effective palliative care in the United States. *The subspecialty these physicians envision, therefore, is not a substitute for the care provided by physicians already connected with patients.* In fact, the need to assure coordination and continuity of care is voiced strongly in interviews and comments from survey respondents. Distinct roles for the palliative care physician that are identified in the surveys including educator, consultant, researcher as well as provider of direct care. A small subspecialty would be able to fill these roles.

Hospitals respondents providing and or planning to provide formal palliative care programs also strongly support the development of formal certification. This should not be a surprise since hospitals prefer and already engage physicians who are voluntarily certified in the programs they provide. This support of certification is consistent with hospitals' high valuation of credentialing of specialists in general.

Advocates believe that an ABMS subspecialty in palliative medicine will provide greater validity to the field and will facilitate research and health system adaptations that are fundamental to improving current approaches to care for patients with chronic and terminal illnesses. For example, ABMS certification will permit tracking of procedure usage that can inform disease, symptom and population management. Legitimizing a formal specialty is also thought to influence future recruitment of physicians to the field. While other countries, e.g. the United Kingdom, already have formal medical subspecialties in palliative care in place that are directed to care of patients with a specific illness, cancer, U.S. advocates are not proposing that palliative care be limited to specific illnesses.

There are other strong voices opposing formal specialization in palliative medicine. This was particularly true among leaders of specialties that frequently care for patients with chronically disabling or terminal illnesses who were interviewed in the study. These physicians were unanimous in opposing the development a new subspecialty. It is notable, however, that *opponents object to the formalization of the field, and not to palliative care*. Some voice concerns that current reimbursement will not attract or sustain physicians in practice. In one interview specialist noted that he was aware of many HIV/AIDS practices could not be sustained because reimbursement levels did not match the acuity of patients' needs. Concern was expressed that the time commitment required in palliative care, as well as potential offloading of patients, could similarly affect palliative care practices. Other physicians believe that a new subspecialty would result in further unnecessary fragmentation within medicine. Here physicians believed that patients' needs can be met within existing specialty structures. They suggest that redesigning health systems to promote better care, such as by establishing palliative care centers of excellence, would be effective alternatives to specialization. Some physicians felt that palliative care is what medicine is all about, that it is intrinsic to the job, and should not be separated into a new field.

While the debate continues, there is agreement that physicians in primary care fields are more likely to be involved in palliative care. The development of a subspecialty would accordingly need to assure pathways enabling physicians in such fields to pursue this interest and practice.

(6) The Value of Educating the Public on Palliative Care

Increased public education and debate regarding the services available to people with serious and life threatening illnesses is recognized as pivotal to the development of future palliative care services. Public debate, including discussion of what constitutes good patient care, as well as private discussions with patients and families regarding treatment options, will serve to increase demand for palliative care services. With the aging of the baby boom generation, concern for adequacy of available services will increase, and pressure for coverage for such services will rise. Increased public demand will strongly reinforce the need for physicians skilled in providing and/or coordinating palliative care for their patients.

While there is consensus within the field that public education is a key strategy to improve the availability and delivery of palliative care, there are significant differences regarding what this care could include. Some in the field regard palliative services as end of life care. Some think it synonymous with hospice care. Others believe that palliative care includes a range of services that should be considered simultaneous to curative treatment and discussed as options with patients at the time of diagnosis of a terminal illness. And still others believe palliative care includes comprehensive care that should be available to individuals affected by any serious medical illness. Mixed messages within the field regarding the definition of services will impact the ability of advocates to educate the public as well as influence public and private reimbursement practices developed to respond to public demands for palliative care.

While physicians responding to the study's survey believed that public education is key to improving care, few allocate time for this among their weekly activities. Only 25% of physicians working in the field 20 or more hours weekly and 6% of the physicians working 9 or fewer hours weekly in palliative care reported participating in public education "all the time or frequently". Therefore, there would seem to be opportunity for physicians to redefine their roles to participate more actively in efforts to educate their communities regarding palliative care.

(7) The Palliative Care Team

The palliative care approach is distinguished by the involvement of a team of individuals able to respond to the range of physical, emotional, spiritual and support service needs of patients and their families. The team approach is believed to maximize resources available to patients and to promote quality of care. Registered nurses, social workers and chaplains are key professionals working with physicians and in hospital programs to deliver palliative care services.

Since group structure and dynamics vary across programs, it is important to document both the roles members of different disciplines play on palliative care teams as well as the nature of the collaboration that occurs among members. Examining the outcomes achieved through different team approaches will benefit planning for implementation of new programs. It will also inform development of training that promotes skill development for team members specific to their fields or specific to work within palliative care teams. Further, documentation of effective team strategies can influence the design of future reimbursement practices.

Current reimbursement practices do not support the team approach in general or coverage of services provided by specific team members. This is seen to frustrate the delivery of comprehensive services to patients in need. Assuring adequate funding for key roles is clearly important for recruitment and retention of personnel in this area. Existing competition for skilled workers in disciplines such as nursing may impact the availability of these professionals to work in palliative care.

Chapter 5: Recommendations to Improve the Delivery of Palliative Care

Palliative care is focused on relief of suffering and improvement in quality of life. As previously described, palliative care is understood to address the comprehensive needs of patients and families with serious disabling conditions, including but not limited to end of life care. The goal of this study has been to identify workforce strategies that will promote the delivery of more effective palliative care in the United States.

The need for system change in this area is well documented: there is recognition that the growth in the numbers of older people in America will outpace the rate of growth for the population as a whole. With the baby boom generation moving into their senior years, the health care system will be severely taxed to provide the care that will be needed. In addition, health care investment has favored scientific, curative interventions at the expense of a focus on reducing suffering. Educational systems training health care professionals reflect this bias, and are now grappling with how to reintegrate palliative care approaches into their training. Investment of public dollars can significantly influence health system design. Reevaluation of allocation of resources through programs such as Medicare and Medicaid are underway in response to growing public and professional attention to this area, as well as in recognition that financing for public programs should anticipate and respond to health needs of those served.

The following strategies and recommendations are offered by the Center for Health Workforce Studies to promote changes in health related service systems that will support improved delivery of palliative care.

Strategy I: Improve education and training in palliative medicine for all physicians serving patients with chronic and life threatening illnesses.

Recommendations for Training New Physicians:

- **Provide physicians with increased opportunities for clinical experiences in palliative care and exposure to physician role models during medical school training.** Clinical experiences are critical for establishing formative practice patterns. Medical schools should be encouraged to use hospital-based palliative care programs and hospices as training sites for their students. Formal palliative care services should be developed, if not already available, in hospitals connected to medical schools.

  Funding positions for palliative care physician educators in medical schools and in clinical programs will further promote desired role modeling. Ryan White Centers, cancer centers, palliative care units, and hospices are examples of clinical programs where educators could be assigned. Foundations and HRSA may wish to consider funding educators in these sites.

- **Increase information sharing among medical schools on approaches taken to integrate palliative medicine into undergraduate, clerkship and residency programs.** Sharing palliative care curricula, case studies, and performance measurement instruments will advance training for new physicians in academic or clinical settings in this field.

  The Bureau of Health Professions, HRSA and the Association of American Medical Colleges are among the groups that may wish to sponsor meetings for deans responsible for curricula development and/ or for supporting survey research that track medical school initiatives.

- **Review medical school curricula and professional association continuing education offerings to assure that "Pain management" and "Communication with patients, family members and staff" are topics covered in training and education programs, and that performance measures are in place permitting feedback to participants on level of skill development.** Physician survey respondents regard these topics as the priority subjects to be taught to physicians to promote knowledge and skill development in palliative care.

Recommendations for the Training of Mid Career Physicians

- **Survey physicians in specialties that frequently treat patients with chronic and terminal illness on the need for, access to and use of emerging palliative care programs.** Understanding the attitudes, practices and training needs of physicians in specialties such as Internal Medicine, Family Practice, and Oncology regarding palliative care will inform medical training initiatives and program planning to increase the expertise of key physician groups in this area of medicine.

- **Convene a strategic planning forum to identify strategies to increase mid career physician understanding and skills in palliative medicine**. Forum participants would include educational experts in "adult learning", medical educators, clinicians, and representatives of professional associations from a spectrum of specialty areas. The group charge would be to develop program and outreach recommendations for increasing expertise in palliative care among distinct groups of physicians: Some physicians already interested in palliative medicine are constrained from pursuing training due to personal and professional commitments. They may need programs and clerkships that are friendly to the "adult learner" and mid-career professional. For others, palliative care is not yet on the radar screen. A planning forum would provide an opportunity to identify strategies to reach different groups of physicians and to influence physician practice patterns in treating patients with chronic and terminal illness.

  Since training all physicians in palliative care is the workforce strategy identified most frequently by physicians and hospitals as important for influencing the delivery of effective palliative care in the U.S. in the study's surveys, multiple strategies are needed to further this objective. HRSA and foundations may wish to consider funding such a planning forum.

- **Expand the availability and sponsorship of EPEC programs so that mid career physicians in specialties that frequently care for patients with chronically disabling and terminal illnesses consider attending**. EPEC programs have proven valuable to many physicians who now affiliate with palliative care professional associations.

National and regional specialty association chapters may wish to cosponsor such training and/or actively encourage participation by their members.

- **Identify opportunities for medical professional associations to collaborate to promote integration of palliative care in treatment of serious illness and to promote skill development among their members.** Leaders of medical specialty groups interviewed believed that their colleagues would support collaborative efforts to develop palliative care services. Sharing approaches taken in the certification and recertification of physicians and/or joint sponsorship of training programs, e.g. communications training, could expand the resources available to improve the quality of care for patients with terminal illness across the United States.

Strategy II. Palliative medicine should become an American Board of Medical Specialties recognized subspecialty.

Recommendation:

- **Palliative Care professional associations should pursue the establishment of a small medical subspecialty in palliative medicine.** Physicians with expertise in palliative medicine are needed as educators, researchers and clinical leaders to raise and address issues relating to the care of chronic and life threatening illness for patients and families. A small cadre of expert physicians will be a resource to others in areas including training, consultation and advocacy for programs. Such a subspecialty is consistent with simultaneous efforts to improve the quality of palliative care provided by all physicians.

  The majority of physician and hospital survey respondents share this vision. There was significant survey respondent support both for educating all physicians in palliative care to better serve the needs of patients and for developing a medical subspecialty in palliative medicine. The subspecialty is not envisioned to supplant physicians already connected to patients.

Strategy III. Clarify the roles that palliative care physicians play in different health care settings.

Recommendation:

- **Examine and compare the roles played by palliative care physicians in settings including hospices, hospitals, nursing homes and academic institutions.** Understanding expectations and requirements for physicians working in formal palliative care programs in different health care settings will influence the education and demonstrated skill levels required for physicians recruited to those programs. Factors to be investigated include how time committed to palliative care influences functions performed, how responsibilities are distributed among health professionals, e.g. RNs, and how reimbursement practices influence functions should be examined. Studies of physician roles will inform development of standards for practice in the field.

Strategy IV. Expand financing for palliative care services.

Recommendations:

- **Reimbursement policies should encourage investment of health care resources in programs that increase the quality of life for patients with serious illness. Sustained and adequate funding streams should be provided to support the development and operation of formal palliative care programs in hospitals and other settings, and to encourage professionals to work in this field.** The current design of public and private payer benefits, including coverage for professional reimbursement and related support services, limit the time, scope and availability of services provided to patients with chronic and/or terminal diagnoses. Study findings demonstrated that current policies constrain physicians' commitment to the practice palliative care, even though a majority of physicians report that they would prefer to work more in this area.

  Reimbursement practices should not discourage a patient's choice of palliative care. The Medicare nursing home hospice care benefit is a more costly option for patients and their families than selection of a curative approach to care in this setting. Medicare and Medicaid programs were not originally designed to address the long term needs of elderly patients suffering chronic illnesses. Funding and services provided through these programs should be reconsidered to respond to the changing demographic and healthcare landscape.

- **Study the impact of current reimbursement policies on the time committed to and role played by physicians providing palliative care services in different health care settings.** Of particular importance is understanding how physicians who work 20+ hours weekly in palliative care are reimbursed since these are the physicians currently performing a majority of palliative care services. Physician reimbursement studies will inform decisions and planning that assure the availability of doctors needed for the provision of high quality care in palliative programs.

- **Adapt state and federal policies to promote coordination of care across settings.**

- **Eligibility criteria for the Medicare Hospice benefit should be *widely clarified* by the Center for Medicare and Medicaid Services.** Confusion exists regarding eligibility for this benefit. For years providers understood that only patients with life expectancies of six months or less would be eligible for hospice. While CMS reports that Medicare will in fact reimburse hospice services beyond the six month period, until there is general clarification of current policy and practice, some providers will defer raising the option of hospice due to reluctance to misdiagnose the timeframe of the course of an illness.

- **Palliative care availability through the Medicare hospice benefit to the treatment of time limited prognoses.** This practice undermines provision of quality care and unduly restricts access to hospice provided palliative care services that can benefit patients at earlier points in their treatment, i.e., while simultaneously seeking curative care. Restricting palliative care to an "end of life" option" unnecessarily limits the use of important patient care interventions that should not be available only as substitutes for curative care. As indicated earlier, seriously ill patients with indeterminate prognoses have been precluded from accessing care, even though they may have preferred incorporating a palliative approach to treatment of a life threatening illness.

- **Medicare, Medicaid and private payer reimbursement policies should reinforce delivery of high quality, cost effective care and that reflect best practices within the**

field of palliative medicine. This should include expanding the range of services covered, the professionals recognized as providing services (team approach to care), and incentivizing specific services (home visits, support services) which will improve quality of care and support care of patients in their homes.

Strategy V. Understand the supply, demand and use of non-physician health care professionals with training in palliative care.

Recommendations:

- **Study the current supply, demand and use of nurses, social workers and clergy who are delivering palliative care services.** Members of these professions are reported to be the professionals who most frequently work with palliative care physicians as well as on formal palliative care hospital teams. Understanding the range of roles they play, as well as their interest and availability to work in the field, are critical to the delivery of palliative care services. Identification of training, recruitment and retention issues will inform workforce planning strategies. This will also facilitate the development of recommendations for professional training and/or reimbursement for services that will encourage a supply of non-physician personnel that reflects anticipated need.
- **Examine the role and needs of caregivers in the delivery of services.**
- **Promote palliative care training for new and midcareer nurses, social workers, clergy and pharmacists.** Palliative care curricula should be incorporated into core professional education programs. The availability of informed health care professionals is essential to the provision of quality palliative care.

Strategy VI. Assure that palliative care services are available to individuals diagnosed with HIV/AIDS.

Recommendations:

- **Physicians working with HIV/AIDS patients should be required to demonstrate understanding and skills in palliative care including the ability to discuss end of life concerns with patients.** Palliative care training and competency testing should be incorporated into academic courses and clinical experiences (rotations, case studies) required for physicians in specialties most likely to treat HIV/AIDS patients (e.g. specialties in infectious diseases and primary care physicians). This will assure exposure of new doctors to physician role models as well as individuals who are dying, and their families. Opportunities for joint palliative care training across specialties and/or clinical departments should be explored during residency years.
- **Communication training to facilitate timely discussion of treatment options, including end of life issues should be required for physicians treating HIV/AIDS patients.** Current research suggests that less than half of HIV/AIDS patients discuss end of life care with their current physicians. The populations increasingly affected by HIV/AIDS include groups with histories of difficulty accessing health care and experiencing discrimination in receiving care. They are also a population that is more

under- treated for pain than cancer patients. Helping physicians to refine skills to communicate more effectively with diverse patients in order to raise issues, clarify preferences, and ascertain appropriate treatment for these patents, will promote quality care. Establishing performance measures and providing feedback to physicians on their effectiveness in communicating with others is important.

- **Explore ways to assure that the resources of palliative care programs are available to HIV/AIDS patients, either through consulting or direct service.** Treatment of HIV/AIDS patients constitutes only a small percentage of the patients accessing services provided by the palliative care physicians and hospitals surveyed. Discussions among palliative care providers and HIV/AIDS providers are needed to assure that palliative care options are available to individuals diagnosed with HIV/AIDS.
- **Under treatment of pain is reported to be significant for HIV/AIDS patients, with women, children and past or current injection drug users identified as particularly vulnerable. Dialogue between treating physicians and palliative care physicians may support development of protocols and treatment for individual patients to more effectively manage pain.**
- **Demonstration of skills in palliative medicine should be considered a requirement in physician job requirements within programs providing HIV/AIDS treatment.**
- **Professional recertification in specialties such as Infectious Diseases should include testing in palliative care.** Professional associations should provide training or alert physicians to programs, such as EPEC programs, to refine skills.

<u>Strategy VII. Increase public understanding of palliative medicine and medical care issues for those with serious illness</u>.

Recommendations:

- **Encourage educational programs that stimulate debate on palliative care at national, state, and local levels.** The public's understanding of options in the care of people with serious illness will influence demand for services provided by health care systems. This is already evident in differences in public policies related to pain management and palliative care services in regions across the country. Providing information to the public on what constitutes good care for this patient population is a key piece of this education. Forums that involve policy makers, health care professionals and the community will promote discussion and development of services reflective of local interest and need.
- **Physicians should be encouraged to increase time committed to pubic education to stimulate discussion of palliative care in their communities.** Physicians report spending limited time in public education activities related to palliative care. These activities would be valuable building support for increased allocation of resources to this area.

Strategy VIII. Identify strategies to embed palliative care into physician practices throughout health care delivery systems.

Recommendations:

- **Document strategies that have proven effective in influencing physician behavior and culture around palliative care issues within or across medical systems in order to facilitate incorporation of palliative care principles in caring for patients with chronic and life threatening illnesses more broadly.** Physician practice patterns can be influenced through interventions including sharing of information and/or standard setting that encourage or require behavior change. Discussing potential strategies and sharing program outcomes in presentations sponsored by specialties, professional associations, and academic programs, as well as in articles for professional journals, will be important to promote changes in physician practice
- **Promote quality initiatives that assure access to palliative care across health care settings.** A broad range of quality initiatives will help promote care responsive to patient needs and preferences. Such initiatives include articulating best practices, clinical guidelines and program standards; establishing professional credentialing practices that require demonstration of palliative care expertise (e.g. for physicians and nurses in specific specialty areas); developing model "job skills and experience" requirements for key professional roles, e.g. Medical Director of a Hospice or Medical Director of a Palliative Care Hospital Unit; and creating material that supports professional and public education around palliative care. Organizations such as JCAHO and NCQA play important roles in influencing healthcare systems, and should be engaged in promoting programs that assure access to palliative care treatment.
- **Conduct research that examines factors that determine patient eligibility to participate in palliative care programs.** Such research may provide insights into issues specific to diseases, patterns of practice and health system design.
- **Document the impact of formal palliative care programs on care provided in health care settings.** Research describing different approaches to the delivery of palliative care services, including the use of health professionals, will assist health care organizations select and implement services to best meet the needs of their communities. Outcomes achieved in different models among categories of settings, e.g. hospitals, hospices and nursing homes, should be examined. Identification of costs and benefits will inform broader program and policy development governing resource allocation in this area. Investigation into models of care that would support palliative care services in rural areas is needed.
- **Fund palliative care research/ centers.** The availability of funding for research will attract physicians to academic centers and will promote development of best practices in this field.