

State of The Discipline
of
Hospice and Palliative
Medicine

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THE AMERICAN BOARD OF HOSPICE AND
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PROGRESS IN MEETING CRITERIA FOR A NEW SUBSPECIALTY

Measured against the criteria of the ABMS and the ACGME, hospice and palliative medicine is now ready to move from an "evolving" discipline to a "mature" discipline in the United States.(1) Already recognized as a separate specialty in other countries (notably Great Britain, Ireland, Australia, and Canada), hospice and palliative medicine has steadily progressed in the United States and is now at a comparable level in terms of interest, need, and infrastructure. (2) The evidence base for the field has developed sufficiently to support an upcoming NIH State-of-the-Science Conference on Improving End-of-Life Care(3), eight peer-reviewed journals, and a dedicated review group of the Cochrane Collaboration. (4) The number of physicians seeking certification in the field is growing, the professional association is strong, and formal training programs are rapidly expanding. During the past several years, the appearance of regular features, clinical practice articles, and research reviews in medical journals with broad readership, such as JAMA and NEJM, demonstrate the interest of the wider medical community in this field (5,6,7).

A BODY OF NEW KNOWLEDGE

The scientific body of knowledge in hospice and palliative medicine finds expression in a variety of scientific and academic endeavors. For instance, the pain, palliative care and supportive care review group of the Cochrane Collaborative has produced more than 50 reviews and 40 protocols. Illustrative Cochrane review topics include Benzodiazepines and related drugs for insomnia in palliative care and Oxygen therapy for dyspnoea. (8) In 2004, The National Consensus Project for Quality Palliative Care published clinical practice guidelines for quality palliative care based on an extensive evidence review and consensus process involving the major United States palliative care organizations (9). Most recently, the National Institute for Health has prepared a State-of-the-Science Conference on Improving End-of-Life Care, which will be held in December 2004. The literature review for the conference covers over 24,000 references published since 1990. (10)

The core body of knowledge for hospice and palliative medicine is expressed by the content outline of the certification examination offered by ABHPM (see attachment 1) and by the program standards for fellowship programs in hospice and palliative medicine. (11) The program standards outline the following core domains of knowledge to be covered by fellowship training:

- Communication
- Ethical and Legal Decision Making
- Pain in Cancer and Non-cancer Patients
- Management of Non-pain Symptoms
- Medical Co-morbidities and Complications in Populations with Life-Threatening Diseases
- Neuro-psychiatric Co-morbidities in Populations with Life-Threatening Diseases

- Psychosocial and Spiritual Support
- Death and Dying
- Bereavement Support for the Family
- Quality Improvement and Research Methodology in Populations with Advanced Illnesses
- The Hospice and Palliative Approach to Care
- Interdisciplinary Team Work

The major skills central to hospice and palliative medicine are the assessment and management of physical, psychosocial and spiritual suffering faced by patients with life-limiting illnesses and their families. Communication and teamwork are critical skills.

THE COMPETENCIES OF THE SPECIALIST LEVEL PRACTITIONER OF HOSPICE AND PALLIATIVE MEDICINE

The 1997 Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*, delineated a three-tiered structure for professional competency in hospice and palliative medicine that corresponds to the primary, secondary, and tertiary levels around which medical care is commonly organized. (13) Primary palliative care is the responsibility of all physicians. This is the type of care relevant to all populations with life-limiting illnesses and is focused on basic approaches to relieving suffering and improving quality of life for the patient and his or her family. Secondary palliative care is the responsibility of individual specialists, or a team of specialists, who typically work in institution-based or community-based palliative care programs or hospice programs. The role of this secondary level of care is to provide consultation and assist in the management of patients who are referred. Tertiary palliative care is the province of academic centers, where new knowledge is created through research, and new knowledge is disseminated through education.

The major competencies of the specialist level hospice and palliative medicine practitioner can be summarized under the broad patient-centered goals of:

- Relieving suffering and sustaining a satisfactory quality of life for patients and families living with life-threatening illness,
- coping well with loss and bereavement, and
- promoting the development and growth possible at the end of life.

While the knowledge domains and skills of hospice and palliative medicine overlap to some extent with the knowledge, attitudes and skills that characterize other disciplines that care for patients with advanced illnesses, the specialty practice of hospice and palliative medicine is distinguished from other disciplines by its exclusive focus on the common problems experienced by diverse populations with life-limiting disease, including the management of the imminently dying patient. Palliative medicine reaches across many disease categories and organ systems to concentrate on relieving the burden of illness.

The specialist level competency required of practitioners in hospice and palliative medicine complements the core competency that should be maintained by other disciplines. The hospice and palliative medicine specialist acquires and applies:

- 1) a higher level of clinical expertise in addressing the multidimensional needs of patients with life-threatening illnesses, including a practical skill set in symptom control interventions,
- 2) a high level of expertise in both clinical and non-clinical issues related to death and dying,
- 3) a commitment to an interdisciplinary team approach, and
- 4) a strong focus on the patient and family as the unit of care.

PUBLICATION OF SCHOLARLY RESEARCH

The emergence of specialized journals, well-regarded textbooks, and formal curricula are all indicators of the development of a new and distinct body of knowledge. Research in the area of hospice and palliative medicine appears in at least eight specialized peer-reviewed journals:

- Journal of Palliative Care (Canada),
- Palliative Medicine (U.K.),
- Progress in Palliative Care (U.K.),
- European Journal of Palliative Care (U.K.)
- Journal of Pain and Symptom Management (U.S.A),
- Journal of Palliative Medicine (U.S.A),
- American Journal of Hospice and Palliative Care (U.S.A),
- Palliative and Supportive Care (U.S.A),

More than one curriculum for hospice and palliative medicine has been published. (14, 15) Models to guide clinical palliative care have been disseminated (16) and a number of textbooks are now available. (17-19) The Oxford Textbook of Palliative Care is now in its third edition and is published by Oxford University Press, which has a specific division for palliative care with 96 current offerings. (20)

GRADUATE MEDICAL EDUCATION

Formal fellowship programs of at least one year in length are expanding rapidly. For the academic year 2000-2001 there were 17 active hospice and palliative medicine fellowship programs of at least a year in length, (21) while by August 2003, there were 43 fellowship programs in operation or in formation. (22) These include six programs funded by the Veterans Administration. The VA program, which is interdisciplinary, adds up to 12 additional slots for physicians wishing advanced training in hospice and palliative medicine. An unpublished survey of fellowship programs identified 47 fellowships in 2004, with a total of 97 fellows.

A survey of all recent graduates (past 5 years) of all hospice and palliative medicine fellowship programs in the United States and Canada identified 101 fellows from 24 programs. The survey found that fellows desired good clinical training; they received large amounts of it and were pleased with it. Upon graduation, the majority of fellows accepted clinically oriented positions, either as full-time clinicians or clinician educators, suggesting that the clinical focus of fellowship training programs is appropriate.

Recognizing that the rapid development of fellowship programs would benefit from the development of common standards, ABHPM and AAHPM jointly established a process for accrediting training programs. The initial step in this process was a consensus process for developing voluntary standards for training. (11) ABHPM and AAHPM appointed a seven-member committee, called the Palliative Medicine Review Committee (PMRC), to implement the standards via an accreditation process. PMRC is closely modeled after ACGME's RRCs. The first accreditation round was conducted in 2004. Nine of the ten applicant programs were successful in achieving accreditation. Applications from an additional ten programs are anticipated in 2005. This process was important because it achieved a consensus on the core content and training requirements within the Palliative Medicine community. By implementing the voluntary accreditation process Hospice and Palliative Medicine training programs have become stronger both individually and collectively. They are in an excellent position to move into the ACGME accreditation process.

BOARD CERTIFICATION

The need for a specialty board was recognized early in the 1990s by the leadership of AAHPM, which encouraged a small working group of hospice and palliative medicine physicians to plan a board that would establish and measure the level of knowledge, attitudes, and skills required for certification of physicians practicing hospice and palliative medicine. This board, ABHPM, was incorporated in 1995. It swiftly established the criteria for entry into the field via an experiential track and gave its first examination in 1996. (23) Since then, more than 1,500 physicians have met the qualifications for certification in hospice and palliative medicine. Most of the candidates have entered the certification process through the experiential track. As fellowship training in hospice and palliative medicine becomes available, a few candidates have gained eligibility to the board via a fellowship in hospice and palliative medicine.

Candidates for the examination are required to have ABMS certification. Overall, 55% reported internal medicine as their primary board, while 23% reported family practice, followed by anesthesiology, neurology, psychiatry, surgery and radiation oncology.

Eligibility for certification is now granted via two tracks: experiential and fellowship. Eligibility via the experiential track requires candidates to meet criteria related to education, training, experience, competence, and professional standing. Candidates who meet these requirements are permitted to sit for the certification examination. The fellowship track is open to fellows who have completed an accredited one-year fellowship in hospice and palliative medicine. (As accreditation is phased in, candidates are permitted entry to certification if the fellowship director of the training program attests that the fellowship substantially meets the voluntary standards for training in hospice and palliative medicine.)

PROFESSIONAL ASSOCIATION

The American Academy of Hospice and Palliative Medicine is the professional association for physicians in hospice and palliative medicine. As of January 2003, AAHPM had 1,600 physician members, 793 of them certified by ABHPM. The Academy supports the dissemination of research, the training of academic leaders, and the continuing education of clinicians in evidence-based practice

through an annual conference; courses for certification preparation and for hospice medical directors; publications, including its Journal of Palliative Medicine; and an awards program including awards for distinguished researchers and young investigators. (24) Its annual assembly, attended by over 1000 physicians and nurses, is the primary forum for the presentation of evidence-based medicine and research in palliative care. Each year, AAHPM presents an award to a distinguished researcher in the field, and a plenary session at the conference is devoted to an overview of the state of the science.

The Academy offers a course in best practice for hospice medical directors and a review of palliative care principles and practice for those preparing for the ABHPM exam. AAHPM was one of five palliative care organizations that published the Clinical Practice Guidelines for Quality Palliative Care that will now support the development and testing of quality indicators for the delivery of palliative care in both hospices and hospital-based palliative care programs.

PRACTICE PATTERNS

The majority of hospice and palliative medicine physicians practice as hospice medical directors and/or as hospital-based consultants. There are now more than 3,200 hospice programs. (25) Medicare-certified hospices are required to have a paid or volunteer staff medical director. The National and Hospice Palliative Care Organization (NHPCO) recently began an initiative to encourage member hospices to strengthen the role and competency of hospice medical directors. (26)

Interest in hospital-based palliative care programs is also growing. The Center to Advance Palliative Care states that 800 hospitals now offer palliative care services and the number appears to be increasing by about 20% annually. (27) The Center for Workforce Studies at the State University of New York documented that physicians currently working within hospice and palliative medicine support formal recognition of the field. (28)

CHALLENGES FOR THE FUTURE

The critical challenge to any specialty or subspecialty is to clearly define the legitimate boundaries of the field. As a subspecialty, hospice and palliative medicine requires training in other fields such as internal medicine and family practice before someone can focus in hospice and palliative medicine. As with other fields, there are areas of overlap with other specialties and subspecialties. Delineating and negotiating those boundaries is an important aspect of the maturation of the discipline. The strong sense of the leadership of the field is that hospice and palliative medicine should continue primarily as a consulting specialty to the other primary disciplines. (29) There is no agenda, expressed or implied, that all suffering and dying patients be cared for by physicians board certified in hospice and palliative medicine.

The broad interdisciplinary nature of hospice and palliative medicine makes it more challenging to define the boundaries of the specialty. ABHPM has deliberately chosen to make room for hospice and palliative medicine's broad interdisciplinary foundation by not restricting entry to a few primary specialties. However, as interest grows by other specialties in improving care within their own domains, the question arises as to whether there are different eligibility or training requirements for pediatricians, surgeons, critical care physicians, emergency physicians, geriatricians, etc., who wish to specialize in hospice and palliative medicine. With the exception of pediatrics, ABHPM currently expects practitioners from any primary discipline to meet the same eligibility standards. Joint training

programs that meet the requirements of both hospice and palliative medicine and other specialties or subspecialties (such as in pediatrics, geriatrics, oncology) are likely to be developed with time.

Another challenge to the field is to build enough capacity within training programs to train the next generation of specialists. The current interest in developing training programs is heartening, but financial resources are scarce and competition for them is strong. Once ACGME recognition is achieved, the potential for federal funding of hospice and palliative medicine training is established, which will yield significant new financial resources for the field. As fellowship training develops, training directors are working creatively to develop pathways for training of the mid-career physician who brings practice experience to the field that is rarely present in recently trained physicians. That maturity likely will continue to be an asset to the field and should not be choked off when formal fellowships become a requirement for entry into the field.

SUMMARY

Palliative medicine has met the criteria that signify the differentiation of a subspecialty area of knowledge and practice. It is now time for the formal structure of the medical profession to acknowledge the importance and relevance of hospice and palliative medicine, and to create a place for the discipline at the table. ABMS recognition of the subspecialty (and subsequent ACGME accreditation of the training) will formalize the role that hospice and palliative medicine already plays in re-discovering, teaching, and upholding a vision of care during illness, dying, and bereavement.

(30)

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ATTACHMENT 1

CONTENT OUTLINE OF CERTIFICATION EXAMINATION IN HOSPICE AND PALLIATIVE MEDICINE

I. Hospice and Palliative Approach to Care

a. Components

- i. Physician Role
- ii. Family and Patient as Unit of Care
- iii. Quality of Life Emphasis
- iv. Interdisciplinary Approach
- v. Relief of Symptoms
- vi. Bereavement Care
- vii. Access to Care

b. Standards of Care

- i. Delivery of Care
 - 1. Home Care
 - 2. Inpatient Care
 - 3. Palliative Care Teams
 - 4. Extended Care
 - 5. Respite Care
- ii. Medical Director
 - 1. Communication
 - 2. Patient Eligibility
 - 3. Consultation
 - 4. Primary Care
 - 5. Quality Improvement
 - 6. Staff Support
 - 7. Team Member
 - 8. Relationships with Colleagues
 - 9. Administrative Responsibilities
 - 10. Marketing
 - 11. Education

- iii. Hospice Medicare Benefit
- iv. Other Reimbursement Mechanisms

c. Education and Research

d. Specific Populations

- i. Children
- ii. Frail Elderly
- iii. Substance abusers

II. Psychosocial and Spiritual Issues

a. Psychosocial Issues

- i. Psychosocial Responses
- ii. Cultural Issues
- iii. Economic Issues
- iv. Family Issues

b. Spiritual Issues

- i. Meaning and Hope
- ii. Spirituality versus Religion
- iii. Religious Beliefs and Practices

III. Impending Death

a. Physiological Changes

- i. Respiratory
- ii. Cardiovascular
- iii. Neurological
- iv. Renal
- v. Gastrointestinal
- vi. Skin and Mucous Membranes

- b. Management of normal impending death**
- c. Management of Complications**

IV. Grief and Bereavement

- a. Anticipatory Grief**
- b. Normal Grief and Bereavement Patterns**
- c. Abnormal Grief and Bereavement Patterns**
- d. Risk Factors**
- e. Therapeutic Interventions**

V. Pain Management

a. Assessment

- i. Concept of Total Pain
 - 1. Physical
 - 2. Psychosocial
 - 3. Social
 - 4. Spiritual/Existential
- ii. Intensity Measurement
- iii. Classification Systems
 - 1. Acute Versus Chronic
 - 2. Nociceptive Versus Neuropathic
 - 3. Other
- iv. Pathophysiology of Pain

b. Analgesics

- i. Nonopioid
 - 1. Pharmacology
 - 2. Side Effects
 - 3. Routes of Administration
 - 4. Equianalgesic Dosing
 - 5. Principles of Use
- ii. Opioid
 - 1. Pharmacology
 - 2. Side Effects
 - 3. Routes of Administration
 - 4. Equianalgesic Dosing
 - 5. Principles of Use
- iii. Adjuvants

c. Additional Interventions

- i. Radiation/Chemotherapy
- ii. Nerve Block/Neuroablation
- iii. Physical and Occupational Therapy
- iv. Acupuncture or TENS
- v. Relaxation and Hypnosis
- vi. Other

d. Barriers to Pain Relief

e. Special Populations

- i. Children
- ii. Frail Elderly
- iii. HIV Disease
- iv. Substance Abusers

VI. Non-Pain Symptom Management

a. Urgent Symptoms

- i. Spinal Cord Compression
- ii. Hypercalcemia
- iii. Increased Intracranial Pressure
- iv. Fractures
- v. Seizures
- vi. Terminal Restlessness or Delirium
- vii. Superior Vena Cava Syndrome

b. Common Symptoms

- i. Anorexia and Cachexia
- ii. Weakness and Fatigue
- iii. Dry Mouth and Oral Lesions
- iv. Dyspnea and Cough
- v. Nausea and Vomiting
- vi. Diarrhea
- vii. Constipation
- viii. Anxiety and Depression
- ix. Confusion
- x. Myoclonus
- xi. Dysuria
- xii. Edema and Ascites
- xiii. Hiccups
- xiv. Insomnia
- xv. Pruritis
- xvi. Incontinence
- xvii. Pressure Ulcers
- xviii. Bowel Obstruction
- xix. Other

c. Psychosocial Issues

VII. Communication and Team Work

a. Communication Skills

- i. Communication Techniques
- ii. Delivering Bad News

b. Family-Centered Approach

- i. Systems Theory
- ii. Counseling Techniques
- iii. Family Conference

c. Dynamics of Interdisciplinary Care

- i. Roles and Functions of Team Members
- ii. Effective Team Work
- iii. Conflict Resolution Skills
- iv. Patient and Family as Team Members

VIII. Ethical and Legal Decision Making

a. Ethical Principles

- i. Autonomy
- ii. Beneficence
- iii. Nonmaleficence
- iv. Justice
- v. Physician Integrity

b. Decision Making

- i. Informed Consent
- ii. Decision Making Capacity/Competency
- iii. Surrogate Decision Making
- iv. Advance Directives
- v. Patient/Family Values
- vi. Principle of Double Effect
- vii. Documentation

c. Patient Rights

- i. Privacy
- ii. Treatment Refusal
- iii. Confidentiality
- iv. Safety
- v. Other

d. Ethics of Physician/Patient Relationship

- i. Non-abandonment
- ii. Respect
- iii. Veracity

e. Professionalism

f. Controversies

- i. Futility
 - 1. Neonatal Issues
 - 2. End of Life Interventions

- ii. Artificial Nutrition and Hydration
- iii. Physician Assisted Suicide
- iv. Voluntary Active Euthanasia
- v. Access to Care/Rationing
- vi. Vegetative State/Brain Death
- vii. Withholding Versus Withdrawing of Care

IX. Prognostication