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Recommended Curriculum Guidelines for Family Medicine Residents

Palliative and End-of-Life Care

This document was endorsed by the American Academy of Family Physicians (AAFP).

Introduction

This Curriculum Guideline defines a recommended training strategy for family medicine residents. Attitudes, behaviors, knowledge, and skills that are critical to family medicine should be attained through longitudinal experience that promotes educational competencies defined by the Accreditation Council for Graduate Medical Education (ACGME), www.acgme.org. The family medicine curriculum must include structured experience in several specified areas. Much of the resident's knowledge will be gained by caring for ambulatory patients who visit the family medicine center, although additional experience gained in various other settings (e.g., an inpatient setting, a patient's home, a long-term care facility, the emergency department, the community) is critical for well-rounded residency training. The residents should be able to develop a skill set and apply their skills appropriately to all patient care settings.

Structured didactic lectures, conferences, journal clubs, and workshops must be included in the curriculum to supplement experiential learning, with an emphasis on outcomes-oriented, evidence-based studies that delineate common diseases affecting patients of all ages. Patient-centered care, and targeted techniques of health promotion and disease prevention are hallmarks of family medicine and should be integrated in all settings. Appropriate referral patterns, transitions of care, and the provision of cost-effective care should also be part of the curriculum.

Program requirements specific to family medicine residencies may be found on the ACGME website. Current AAFP Curriculum Guidelines may be found online at www.aafp.org/cg. These guidelines are periodically updated and endorsed by the AAFP and, in many instances, other specialty societies as indicated on each guideline.

Each residency program is responsible for its own curriculum. **This guideline provides a useful strategy to help residency programs form their curricula for educating family physicians.**

Preamble

Caring for dying patients is as much a part of family medicine as are efforts to improve patients' lives. As patients live longer, more people live with chronic health conditions, and the aging and terminally ill populations continue to grow. It is vital to ensure family physicians are appropriately trained to provide high-quality palliative and end-of-life care.

One important element of palliative and end-of-life care is allowing terminally ill patients to die with as much dignity, comfort, and control as possible. Palliative medicine is focused on improving quality of life for patients for whom a cure is not possible, available, or the primary goal. Many of the tenets intrinsic to the specialty of family medicine are important in the care of individuals at the end of life. A holistic approach to each patient's physical and psychosocial well-being, a focus on the family, continuity of care, and an emphasis on quality of life are four important principles that make the family physician uniquely suited to care for people who have terminal illnesses.

The end of life is a critical time in the physician-patient relationship. Palliative medicine may be combined with other treatments or modalities with a therapeutic goal, or it may be the complete focus, as in hospice care. A family physician providing and coordinating hospice or other team care for a dying patient can ease physical symptoms and provide social, emotional, and spiritual support to the patient and their loved ones. Appropriate instruction and experiences in palliative and end-of-life care throughout residency training will provide vital knowledge to help ease pain and suffering and will inspire family physicians to participate in an important moment of continuity of care: care at the end of life.

Competencies

At the completion of residency training, a family medicine resident should be able to:

- Identify and manage a plan of care based upon a comprehensive interdisciplinary assessment of the patient's and family's expressed values, goals, and needs for palliative and end-of-life care (Patient Care, Medical Knowledge, Interpersonal and Communication Skills)
- Effectively communicate a palliative care plan, as well as an end-of-life care plan, to the patient and their family (Patient Care, Medical Knowledge, Interpersonal and Communication Skills)

- Identify and accept a patient's definition of quality of life, and consider how to apply this definition to the patient's care plan (Patient Care, Interpersonal and Communication Skills, Practice-based Learning and Improvement, Professionalism)
- Identify the primary decision maker when the patient is unable to communicate and/or make medical decisions. Describe ethical, local, and national legal issues that may limit or be the basis of a terminally ill patient's preferences and choices. (Practice-based Learning and Improvement, Interpersonal and Communication Skills, Systems-based Practice, Professionalism)
- Facilitate patient autonomy and access to information while providing palliative care throughout the continuum of illness by addressing physical, emotional, social, and spiritual needs (Patient Care, Medical Knowledge, Interpersonal and Communication Skills, Professionalism)
- Recognize the signs and symptoms of a patient who is imminently dying and anticipate the patient's and family's needs (Medical Knowledge, Patient Care, Interpersonal and Communication Skills)
- Demonstrate systematic recognition, assessment, and evidence-based education and management of common end-of-life symptoms, including dyspnea, hunger/thirst, anxiety, delirium, and pain. Manage these symptoms using both pharmacologic (opiate and nonopiate) and nonpharmacologic treatments and be aware of possible side effects. (Patient Care, Medical Knowledge, Practice-based Learning and Improvement)

Attitudes

The resident should demonstrate attitudes that encompass:

- Respect for the psychosocial, cultural, spiritual, and religious issues affecting terminally ill patients and their family members
- Appreciation for the benefits, limitations, and appropriate use of advance directives and Physician Orders for Life-Sustaining Treatment (POLST)
- Contemplation of ethical and historical contexts of palliative care and hospice care and how these may affect acceptance of end-of-life care options
- Compassion for and understanding of the dying patient's need for palliative care, pain relief, control, and dignity
- Reverence for the bereavement process for the dying patient and family members during the continuum of illness and after death
- Reflection on the special issues associated with children, either as terminally ill patients or as family members of a terminally ill patient

Knowledge

In the appropriate setting, the resident should demonstrate the ability to apply knowledge of:

1. Palliative and end-of-life care
    a. Definition of palliative care
        i. Appropriate at any stage in the setting of a serious illness
        ii. Can be provided concurrently with treatments with curative or life-prolonging intent
        iii. Provided over time based on needs (not prognosis)
    b. Definition of hospice care
        i. Appropriate at the end stages of a serious illness and/or at the end of life when a patient has approximately six months or less remaining life expectancy
        ii. Typically provided in lieu of treatments with curative or life-prolonging intent
    c. Continuum from care with curative intent to palliative care to hospice care
    d. Mission
        i. Improvement of quality of life by attending to physical, functional, psychological, practical, and spiritual consequences of a serious illness
        ii. Alleviation of suffering
        iii. Autonomy of the patient
        iv. Person- and family-centered care
    e. Epidemiology
        i. Aging population
        ii. Most common chronic illnesses and illness trajectories
        iii. Most common causes of death by age
        iv. Cost of care for terminally ill patients in various settings
        v. Where people die
        vi. Survival rate and rates for discharge home after receiving life-sustaining treatment (cardiopulmonary resuscitation [CPR], intubation)
2. The eight domains of quality hospice and palliative care
    a. Structure and processes of care
        i. Care locations
            1) Hospital-based care
                a) Inpatient
                b) Intensive care unit (ICU)

            c) Emergency department
        2) Community-based care
            a) Outpatient
            b) Extended care facility
            c) Home
    ii. Interdisciplinary team
        1) Physician
        2) Nurses
        3) Caregivers
        4) Pharmacists
        5) Home health aides
        6) Social workers
        7) Chaplain
        8) Volunteers
    iii. Hospice
        1) Eligibility guidelines
        2) Certification of terminal illness
        3) Services covered
        4) Barriers to use
        5) Statistics/patterns of use
            a) Time enrolled
            b) Services used
            c) Populations served
            d) Disparities
b. Physical aspects of care
    i. Pain
        1) Physiology
            a) Total pain: inclusive of spiritual, physical, and existential components
            b) Chronic
            c) Somatic
            d) Neuropathic
            e) Visceral

        2) Assessment
            a) Multidimensional
            b) Patient expectations, goals, and concerns
            c) Review of data
        3) Management
            a) Opiates
                - Conversion of opiates using equianalgesic table
                - Routes of administration
                - Titration
                - Rotation
                - Addiction, habituation, and dependence
                - Management of side effects
            b) Nonopiate and adjuvant analgesics
            c) Complementary and alternative medicine
            d) Nonpharmacologic pain control measures
    ii. Nonpain symptom management
        1) Dyspnea
        2) Sleep issues
        3) Depression
        4) Anxiety
        5) Cough
        6) Seizures
        7) Fatigue
        8) Nausea and vomiting
        9) Oral secretions
        10) Constipation
        11) Anorexia and cachexia
            a) Role of artificial feeding, intravenous fluids, and/or comfort feeding
        12) Dysphagia
        13) Delirium
    iii. Deprescribing medications
    iv. Prognostication

        1) Surprise question
        2) Karnofsky index
        3) ECOG scale
        4) Palliative Prognostic Score
        5) Mortality risk index
        6) FAST Scale

c. Psychological and psychiatric aspects of care
    i. Bereavement process
        1) Normal grief reaction
        2) Adjustment disorder or dysfunctional grieving process
    ii. Clinician self-care

d. Social aspects of care

e. Spiritual, religious, and existential aspects of care
    i. Spiritual assessment

f. Cultural aspects of care
    i. Communication
        1) Patient-centered goals
        2) Shared decision making
        3) Estimation of prognosis
        4) Empathy
        5) Barriers to communication

g. Care of the imminently dying patient
    i. Recognizing signs of impending death
    ii. Palliative sedation

h. Ethical and legal aspects of care
    i. Patient competency
    ii. Advance directives
    iii. Do-not-resuscitate (DNR) orders
    iv. Physician Orders for Life-Sustaining Treatment (POLST) forms
    v. Durable power of attorney for health care
    vi. Withholding and withdrawal of life support
    vii. Pronouncement of death

    viii. Completion of death certificate
    ix. Physician-assisted dying

Skills

In the appropriate setting, the resident should demonstrate the ability to independently perform or appropriately refer the following skills:

1. Perform an accurate physical assessment with attention to common findings of the terminally ill patient

2. Deliver bad news compassionately and empathetically to both individuals and families

3. Estimate and communicate prognoses and their limitations to patients and families

4. Facilitate a family meeting to elucidate goals of care and quality-of-life expectations for both the patient and caregiver(s) through expectation setting, value sharing, and identification of cross-cultural and spiritual issues that can drive decision making; understand the impact of this process on the patient and family members

5. Determine patient preferences regarding CPR and appropriately document “code status” in the medical record and physician orders

6. Compare and contrast hospice care and palliative medicine

7. Identify patients who are hospice eligible or near eligible through appropriate application of hospice and frailty guidelines

8. Comply with regulations pertaining to use of controlled substances for the terminally ill patient in and out of hospice care

9. Develop a treatment and management plan for palliative care that includes:
    a. An initial and ongoing symptom management regimen
    b. Counseling and discussion with the patient and family members about expectations, signs of change, and transitions of care points

10. Use appropriate routes of analgesia effectively
    a. Oral
    b. Intravenous
    c. Rectal
    d. Topical (e.g., creams, gels, patches)
    e. Nasal

    f. Subcutaneous
    g. Sublingual
    h. Inhaled via nebulizer

11. Refer patient and caregivers to available social services related to:
    a. Financial or social service needs
    b. Legal needs (advance directives, surrogate decision makers, end-of-life decision act)
    c. Psychological needs, including bereavement

12. Function as a contributing team member of the interdisciplinary team by understanding the roles and expectations of other team members, including social workers, chaplains, nurses, respiratory therapists, psychologists/therapists, and other physicians

13. Communicate patient and family goals regarding care plans to other members of the patient care team

14. Engage in self-care and seek support for wellness as a health care professional

Implementation

This curriculum should be taught in a combination of longitudinal and block learning experiences throughout residency training. The curricular content should be integrated into the core didactic schedule on a recurring basis. The content should include instruction regarding palliative and hospice care; how to have conversations with families about the two; how to identify goals of care and quality-of-life expectations in various care settings as part of an interdisciplinary team; and bereavement counseling, when possible. Clinical exposure should include rotations with inpatient and outpatient palliative and hospice care teams, home visits, and opportunities to lead family meetings. Relevant literature should be regularly reviewed and integrated into the curriculum. Patients who have terminal illnesses should be included in all resident patient panels. Faculty members should function as role models for residents in the care of dying patients and their families. Active learning techniques such as role-playing, patient simulations, case discussions, and topic presentations are preferred.

Resources

American Academy of Hospice and Palliative Medicine. *Primer of Palliative Care.* 7th ed. AAHPM; 2019.

Back A, Arnold R, Tulsky J. *Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope.* Cambridge University Press; 2009.

Booth S, Edmonds P, Kendall M. *Palliative Care in the Acute Hospital Setting: A Practical Guide*. Oxford University Press; 2009.

Bruera E, Higginson IJ, von Gunten CF, et al., eds. *Textbook of Palliative Medicine and Supportive Care*. 2nd ed. CRC Press; 2016.

Byock I. *Dying Well: Peace and Possibilities at the End of Life*. Riverhead Books; 1998.

Carter BS, Levetown M, Friebert SE, eds. *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. 2nd ed. Johns Hopkins University Press; 2011.

Cherny N, Fallon M, Kaasa Stein, et al., eds. *Oxford Textbook of Palliative Medicine*. 5th ed. Oxford University Press; 2015.

Gawande A. *Being Mortal: Medicine and What Matters in the End.* Metropolitan Books; 2014.

Goldstein NE, Morrison RS. *Evidence-Based Practice of Palliative Medicine*. Saunders; 2012.

Hui D, Reddy A, Bruera E. *50 Studies Every Palliative Care Doctor Should Know.* Oxford University Press; 2018.

Kübler-Ross E. *On Death and Dying*. Classics ed. Simon and Schuster; 2014.

Lo B. *Resolving Ethical Dilemmas: A Guide for Clinicians*. 6th ed. Lippincott Williams & Wilkins; 2019.

Lynn J, Schuster JL, Wilkinson AM, et al. *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*. 2nd ed. Oxford University Press; 2007.

Macauley RC. *Ethics in Palliative Care: A Complete Guide*. Oxford University Press; 2018.

McPherson ML. *Demystifying Opioid Conversion Calculations: A Guide for Effective Dosing*. 2nd ed. ASHP; 2018.

Meier DE, Isaacs SL, Hughes RG, eds. *Palliative Care: Transforming the Care of Serious Illness*. Jossey-Bass; 2011.

Volandes AE. *The Conversation: A Revolutionary Plan for End-of-Life Care.* Bloomsbury; 2016.

Watson M, Campbell R, Vallath N, et al., eds. *Oxford Handbook of Palliative Care*. 3rd ed. Oxford University Press; 2019.

Website Resources

Ariadne Labs. Serious Illness Care. www.ariadnelabs.org/areas-of-work/serious-illness-

care/

Center to Advance Palliative Care. www.capc.org

Conversation Project. https://theconversationproject.org/

Deprescribing.org. What is Deprescribing? https://deprescribing.org/what-is-deprescribing/

ePrognosis. https://eprognosis.ucsf.edu/

GeriPal. www.geripal.org

Go Wish. http://gowish.org/

Hospice by the Bay. Hospice eligibility requirements. http://hospicebythebay.org/resources/lcd-and-physician-letter-3-15-16.pdf

National Coalition of Hospice and Palliative Care. National Consensus Project for Quality Palliative Care (NCP). www.nationalcoalitionhpc.org/ncp

Palliative Care Network of Wisconsin (PCNOW). Fast Facts and Concepts. www.mypcnow.org/fast-facts/

Prepare for Your Care. https://prepareforyourcare.org/welcome

The Patient Preferences Project. Best case/worst case scenario communication tool. www.youtube.com/watch?v=oXfXr7koz_A

VitalTalk. www.vitaltalk.org/resources

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