

Understanding and Accessing Palliative Care Services for Patients with Progressive Illnesses

Gina M. Basello, DO¹; Alan R. Roth, DO²

¹Residency Director, Family Medicine Residency Program, Associate Director, Hospice and Palliative Medicine Fellowship Program

²Chairman, Department of Family Medicine, Director, Hospice and Palliative Medicine Fellowship Program
Jamaica Hospital Medical Center

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- Goals of care
- Hospice
- End-of-life care
- Prognostication

As our country’s population ages, there are more patients with advanced chronic illness and increasingly complex care needs. Our rapidly changing healthcare environment now recognizes the importance of improving care quality to achieve better health outcomes while lowering cost and improving patient satisfaction. This focus solidified the emergence of Palliative Care as an essential specialty to provide the comprehensive care that these patients with advanced chronic illness require. Palliative Care assists patients and families with difficult decision-making, addresses pain and other distressing symptoms, helps prolong life, controls costs, and most importantly, improves patient and family satisfaction. To maximize the benefits of palliative care, practicing Family Physicians need to develop primary palliative care knowledge and skills while recognizing when specialty level palliative care is required. Prognostication is an essential skill as it allows patients and families to establish realistic goals of care that will guide medical decision making throughout the disease trajectory. In all settings, primary and specialty level palliative care is best delivered by an interdisciplinary team with the Family Physician as an essential team member.

Our nation’s population is aging, and with these changing demographics, more Americans suffer from advanced chronic illness with their corresponding needs increasing in complexity. Meeting the needs of these patients requires healthcare professionals to provide comprehensive care while practicing within an already overburdened healthcare system. These are not easy clinical challenges. Our rapidly changing healthcare environment now recognizes the importance of improving care quality to achieve better health outcomes while lowering cost and improving patient satisfaction. This focus solidified the emergence of Palliative Care as an essential specialty and made evident the need of the practicing Family Physician to develop primary palliative care knowledge and skills.¹

Clear and convincing evidence exists that Palliative Care assists patients and families with difficult decision-making, addresses pain and other distressing symptoms, helps prolong life, controls costs, and most importantly, improves patient and family satisfaction.²

There are numerous definitions of Palliative Care that describe the patients that are appropriate for Palliative Care, the scope of services offered, and the benefits of this advanced level of care. (See Table 1)

Address correspondence to: Gina M. Basello, D.O, Residency Director, Family Medicine Residency Program, Associate Director, Hospice and Palliative Medicine Fellowship Program, Jamaica Hospital Medical Center, 8900 Van Wyck Expressway, Jamaica, NY 11418
Phone: 718-206-6748; Email: gbasello@jhmc.org

Table 1: Definitions of Palliative Care^{3,4}

World Health Organization (WHO) Definition of Palliative Care
<p>Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative Care:</p> <ul style="list-style-type: none"> • Provides relief from pain and other distressing symptoms; • Affirms life and regards dying as a normal process; • Intends neither to hasten or postpone death; • Integrates the psychological and spiritual aspects of patient care; • Offers a support system to help patients live as actively as possible until death; • Offers a support system to help the family cope during the patients illness and in their own bereavement; • Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; • Will enhance quality of life, and may also positively influence the course of illness; • Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Centers for Medicare & Medicaid Services (CMS)

Definition of Palliative Care

“Palliative care” means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

All versions of the definition emphasize that the priorities of Palliative Care center on the patient and family to improve quality of life, relieve suffering, establish goals of care, manage physical symptoms, address psychosocial issues and coordinate care as a team effort.

These priorities require an individualized comprehensive approach to each patient that considers the entire spectrum of physical and psychosocial needs. The cornerstone of the care for these patients is the establishment of appropriate goals of care. This necessitates a precise and thorough patient evaluation, the utilization of general and disease specific prognostication tools, clinical judgment and sound communication skills. Subsequently, all medical decision making should be guided by the established care goals, and as the illness progresses, reconsideration of individual needs across the entire palliative care spectrum must occur on a continual basis. (See Table 2)

Table 2: Domains of Palliative Care

- Pain Management
- Non-Pain Symptom Management
 - Dyspnea
 - Delirium
 - Diarrhea/Constipation
 - Anxiety/Depression/ Sleep Disturbances
 - Anorexia/Cachexia/Weight loss
 - Fatigue
- Establishing Goals of Care/Difficult Decision Making
- Prognostication
- Communication Skills
 - Delivering Bad News
 - Conducting a Family Meeting
- Addressing Advanced Directives
- Issues Related to Artificial Hydration and Nutrition
- Complex Psychosocial Issues
- Hospital Discharge Planning and Patient Disposition
- Care of the Actively Dying Patient
- Ethical Issues
- Cross-Cultural Issues
- Palliative Care Emergencies
- Palliative Sedation
- Withdrawal/Withholding Treatment

A common misconception exists among physicians and patients that Palliative Care is synonymous with hospice

care. Though both of these services are part of a treatment continuum for those patients with chronic complex illnesses and both focus on quality and comfort, significant differences exist. Most importantly, Palliative Care should occur from the time of the diagnosis of chronic disease to be most beneficial.⁵

Many physicians mistakenly consider Palliative care as a last resort measure, and unfortunately, integrate these services at a point in the disease trajectory that prevents both patients and their families from receiving maximal benefit of these quality services. (See Table 3)

Table 3: Hospice vs. Palliative Care

Hospice	Palliative Care
Prognosis of 6 months or less	Anytime during the illness
Must forgo curative measures	May be combined with curative care
Medicare Hospice Benefit	Independent of payer
Disease specific eligibility criteria	Any stage of chronic complex illness
Includes social and bereavement services	Includes social services

One of the fundamental principles of both comprehensive hospice and palliative care is the recognition that a multidisciplinary team approach is necessary to meet the complex care needs of patients and families with advanced illness at any stage.⁶ (See Table 4)

Table 4: The Palliative Care Interdisciplinary Team

- Patient and Family
- Primary Physician
- Consultant Physicians
- Nurse Practitioner
- Physician Assistant
- Nurses
- Chaplain
- Social Worker
- Physical and Occupational Therapist
- Psychologist
- Clinical Pharmacologist
- Nutritionist
- Volunteers
- Administrators
- Community Health Workers

The identification of patients appropriate for palliative care services requires an awareness of the complexity and stage of the illness and any existing comorbidities, an understanding of the disease’s typical trajectory, the realization of disease burden and the corresponding care needs of the patients

and their families. Physicians must be able to accurately prognosticate to allow for the establishment of realistic care goals that will guide the treatments offered and the potential benefits.⁷ (See Table 5)

Table 5: Patients Appropriate for Palliative Care

- Advanced Chronic Complex Medical Illness
i.e. congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), dementia, cancer, end-stage renal disease (ESRD), end-stage liver disease (ESLD)
- Multiple Comorbidities
- Expected Limited Prognosis <3 years
- Homebound
- Family Conflicts
- Frequent Emergency Department Visits, Hospital Admissions or Readmissions
- Poor Functional or Performance Scale
- Elderly, Debility, Adult Failure to Thrive, Frailty and Increased Dependency
- Complex Medical Needs
- Frequent Symptoms

One of the major challenges associated with selecting patients that are appropriate for Palliative Care is the fluctuating course of a medical illness that limits the sensitivity of accurate prognostication. The development of prognostication skills is essential for both the primary care physician as well as the palliative care specialist.

Accurate prognostication provides patients and their families with the information essential to being able to decide upon goals of care, determine priorities and have reasonable expectations over the course of the illness.

The dying trajectory refers to changes in health status over time as a patient approaches death. Cancer, in general, has a predictable trajectory with a steady decline over the last months of life. Other disease processes, such as Congestive Heart Failure and COPD, are more difficult to predict as these conditions are associated with repeated exacerbations and remissions.⁸

The functional status of the patient is the most important factor in determining prognosis, regardless of the primary disease process. Multiple tools exist to aid the clinician in this essential assessment. These tools take into account level of activity, intake, level of consciousness and activities of daily living in scoring overall functional status. Exclusive of the use of any tool, physician estimation of patient survival is an independent, important and accurate element in determining prognosis. However, it has been shown that prognostic accuracy is inversely related to the closeness of the continuity patient-physician relationship as physicians tend to significantly overestimate survival for their continuity patients.⁹ Disease

specific tools for measuring prognosis are readily available for common chronic diseases such as dementia, CHF, COPD, and end-stage liver and renal diseases. Many of the disease specific prognostication tools incorporate functional status into the predictive measurements. (See Table 6)

Table 6: Prognostication Tools

General Prognostication Tools

- Karnofsky Performance Scale¹⁰
- Palliative Performance Scale¹¹

Biological Data Considerations

- Advancing Age
- Weight Loss > 10%
- Elevation in Blood Urea Nitrogen (BUN), Creatinine, B-Type Natriuretic Peptide (BNP) and Bilirubin
- Decrease in Albumin

Disease Specific Prognostication Tools

- FAST (Functional Assessment Staging for Dementia)¹²
- MELD (Model for End-Stage Liver Disease)¹³
- Seattle Heart Failure Model¹⁴
- ECOG Performance Status (Eastern Cooperative Oncology Group)¹⁵
- SEER (National Cancer Institute Surveillance, Epidemiology and End Results)¹⁶
- BODE (Body-Mass Index, Airflow Obstruction, Dyspnea and Exercise Capacity Index in COPD)¹⁷

As the specialty of Palliative Care continues to evolve, the aging population and its increased complexity of illness will require all Family Physicians to become competent in the delivery of what is now known as “Primary Palliative Care.” This would be the most ideal and sustainable delivery model for patients requiring this advanced level of care.

Primary Palliative Care is best delivered by the provider who has the closest relationship with the patient and family. Most patient symptoms, psychosocial issues, and advanced care planning can, and should, be addressed in the non-emergent ambulatory setting of the physician’s office. Providing optimal patient-centered end-of-life and palliative care to Americans in a medical home requires that physicians become proficient in navigating doctor-patient relationships, in developing skills for delivering bad news, in prognosticating accurately, in establishing culturally appropriate and patient-centered goals of care, in addressing advance planning and in assessing and treating pain and the other physical symptoms associated with advanced chronic illness. Equally important is that providers of palliative and end-of-life care must become aware of their own views and values regarding illness and death, and how these may impact the care they provide.

Secondary or specialist-level Palliative Care should only be necessary for complex pain and symptom management,

challenging care decisions regarding the use of life sustaining treatments or when the primary provider is not readily available. Even in the cases where specialist level palliative care is required, the Family Physician, working as an integral member of the healthcare delivery team, can ensure that the goals of the patient and family are appropriately met as the continuity relationship with their patients and families is irreplaceable.^{7,18}

Primary care physicians need to understand the scope of primary and specialty level palliative and end-of-life care to ensure that patients receive the advanced level of care that they require in all settings. Various delivery models exist for Palliative and End-of-Life Care. Criteria exist to guide the primary care physician in the determination of which patients are appropriate for palliative care or hospice care in multiple care settings. Despite the location, this advanced level of care is provided by an interdisciplinary team, and ideally, with the primary care physician as an essential member of the team. (See Tables 7 and 8)

Table 7: Palliative and End-of-Life Care Delivery Models

- Hospital Palliative Care Consultation Service
- Ambulatory Palliative Care Centers
- Home Based Palliative Care Programs
- Dedicated Hospital Palliative Care Unit
- Hospice Care (Home, Hospital, Long-Term Care, Assisted Living, Stand-alone Hospice Center)

To achieve the goal of Family Physicians providing primary palliative care and specialist level palliative care being reserved for difficult-to-manage symptoms, complex family dynamics and challenging care decisions, education and training of primary care physicians in primary palliative care must become an essential component of our healthcare system to best address the needs of these patients, ensure quality care throughout the disease trajectory and lower costs through improved allocation of resources. There are numerous resources and educational programs available for the primary care physician to utilize in developing the necessary knowledge and skills to provide comprehensive primary palliative care to their continuity patients with advanced chronic illness. (See Table 9)

Table 9: Resources for Hospice and Palliative Care Education and Training

Resource	Website
Center for Advancement of Palliative Care	capc.org
EPERC (End of Life Palliative Education Resource Center)	eperc.mcw.edu
American Academy of Hospice and Palliative Medicine	aahpm.org
National Hospice and Palliative Care Organization	nhpco.org
End-of-Life Nursing Education Consortium (ELNEC)	aacn.nche.edu/ELNEC
National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care	nationalconsensusproject.org/Guidelines

Table 8: Hospital-Based Palliative Care Consultation Criteria

A Palliative Care Consult should be considered in any of the following contexts:			
<p>A. Primary Disease Process</p> <ul style="list-style-type: none"> • Cancer (Active/Metastatic/ Recurrent) • Advanced COPD • Advanced CHF (EF<25%) • Cardio-Respiratory Arrest with Cerebral Hypoxia/Anoxia • Shock with MODS • Advanced Neurodegenerative Disease (e.g., Dementia, Parkinson's, Amyotrophic Lateral Sclerosis ALS) • ESRD and/or ESLD • Stroke with at least 50% decreased functional ability • Actively dying patient 	<p>B. Concomitant Factors</p> <ul style="list-style-type: none"> • Hemodialysis • Liver Disease • Moderate CHF, Coronary Artery Disease (CAD), Severe Valvular Disease, Cardiomyopathy, Pulmonary Hypertension • Bed-bound/Dysphagia/Failure to Thrive/Functional Decline/ Pressure Ulcers • Complex medical decision making/Family disagreements/Conflicts about care • Patients from Long-Term Care Centers • Patients on home hospice 	<p>C. Other Criteria to Consider The Patient is/has:</p> <ul style="list-style-type: none"> • A life-limiting illness • Unacceptable level of pain > 24 hours • Uncontrolled symptoms (i.e., dyspnea, nausea, vomiting, anxiety) • Frequent visits to the emergency department • More than one hospital admission for the same diagnosis in the last 30 days • Prolonged intensive care unit (ICU)/hospital stay without evidence of progress or improvement • Transferred from hospital floor to ICU • S/P cardiorespiratory arrest • Medical Futility 	<p>D. Call consult before discussions about:</p> <ul style="list-style-type: none"> • PEG tube for artificial nutrition • Tracheostomy for prolonged mechanical ventilation • Shiley or Permacath for Hemodialysis • Withdrawal of ventilatory support

The number of patients needing palliative care services will continue to increase as our nation continues to age. This trend, combined with a relative shortage of Palliative Care specialty physicians, necessitates that primary care physicians develop these essential primary palliative care skills to create better outcomes, lower cost and improve patient and family satisfaction.

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May/June 2014 Answers:

1. d 2. d 3. a 4. c 5. d 6. b 7.a 8. b 9. c 10. a