

15 · Palliative and Hospice Care



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PALLIATIVE AND HOSPICE CARE

Palliative care addresses the physical, emotional, social, and spiritual needs of patients and families. It offers vigorous treatment of pain and other symptoms; relief from worry, anxiety, and depression; close communication about care; well-coordinated care during illness transitions; support for family caregivers; and a sense of safety in the healthcare system.¹

THE FOCUS OF PALLIATIVE CARE is promoting quality of life by preventing, treating, and relieving pain and suffering and other debilitating effects of illness experienced by patients and families.

Palliative and Hospice Care: A New Paradigm of Care

PALLIATIVE CARE is a new paradigm of care that is moving into the mainstream of healthcare. It is both a philosophy of care and an organized, highly structured system for delivering care for any patient and family experiencing serious, progressive, chronic, or life-threatening illness at any point during the illness experience.²

To achieve maximum benefit, palliative care ideally begins at the time of diagnosis with a life-threatening illness and continues throughout the course of illness until the death of the patient and into the bereavement period of families.³ Offered by an interdisciplinary team of health professionals, palliative care responds to both the episodic and long-term nature of multifaceted illness. Given that it is not dependent on prognosis, palliative

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care can be delivered at the same time as curative or life-prolonging treatments are being offered or as the main focus of care when solely comfort and supportive interventions are desired.⁴

Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and families, optimizing function, helping with decision-making, and providing opportunities for personal growth.⁵ It is important to recognize that palliative care is focused on matching treatments with the patient's and family's values and preferences.⁶ Palliative care involves the integration of the best evidence possible regarding treatments, with the clinical judgment of health professionals, while taking into account the wishes and preferences of patients and their families.

In contrast to palliative care, which begins at the time of diagnosis with any life-threatening illness and continues throughout the illness experience, hospice care provides care to patients who have a prognosis of six months or fewer to live. The focus of hospice care is the care of patients and families during the last months and days of life. Both palliative care and hospice care are based on the same key elements: the care of all patients with life-threatening illness of all ages, patient- and family-centered care, and comprehensive care (physical, emotional, social, and spiritual) offered by an interdisciplinary team of health professionals.

There are several clinical models of palliative care including programs offered in hospitals through palliative care consultation services or on inpatient palliative care units, as well as in nursing homes, assisted living facilities, community home-based programs, or outpatient clinics. Hospice care is also offered in a variety of settings including hospice units in hospitals, hospice care in nursing homes, residential hospices, and home hospice. Today, many hospices are providing palliative care so that patients who have greater than six months prognosis may also receive the holistic support needed to promote their quality of life. Therefore, the difference between palliative care and hospice care is the timing: palliative care may be offered at any point in time while hospice care is offered at the end of life.⁷

The Need for Palliative and Hospice Care

PALLIATIVE CARE HAS BEEN INCREASINGLY IN DEMAND due to the aging of the population and an increase in life expectancy of patients with cancer, HIV/AIDS, and end-stage organ diseases. Public awareness, the education of health professionals, Joint Commission Accreditation, and the desire for Magnet status (an award given by the American Nurses Credentialing Center to hospitals that satisfy a set of criteria designed to measure the strength and quality of their nursing) by hospitals has served as the impetus for an increase in palliative care consultations and hospice referrals. Media attention has informed patients and families that they have a right to expect relief of pain and other symptoms; support for psychological, psychiatric, spiritual, or social distress; active involvement in decision-making regarding treatment options; and consideration of their wishes and preferences. The importance and value of palliative care is highlighted by the following data:

- The US population ages 85 and over is expected to grow from 5.3 million in 2006 to nearly 21 million by 2050.⁸
- The sickest 10% of the US population accounts for 64% of healthcare expenditures.⁹
- Palliative care consultation reduces the cost per patient by almost \$1,700 for live discharges and almost \$5,000 for patients who die in the hospital. This is an annual cost savings of more than \$1.3 million per year for a 400-bed hospital.¹⁰
- In 2006, 67% of Maryland hospitals with more than 50 beds reported the presence of a palliative care program.¹¹

PALLIATIVE CARE is emerging at a time when Marylanders most need it to complement current cancer care. Cancer is the second leading cause of death in the state of Maryland, with one of every four deaths attributed to cancer. It is estimated that in 2009, Maryland had more than 26,000 new cancer patients diagnosed (excluding basal and squamous cell skin cancers), and more than 10,000 deaths.¹² More individuals and families are living with cancer as a “chronic disease,” which increases the need for expert survivorship care. The aging population and improvements in cancer

treatment mean that the number of survivors will grow, and more than half of those diagnosed will live for more than five years with illness and ongoing treatment.¹³

Palliative care is poised to become a universally available approach to meet the needs of the sickest and most vulnerable populations and is an important factor in improving healthcare in the US.¹⁴ This is based on data that palliative care outcomes include:¹⁵

- Improvement of quality while lowering cost of hospital care.
- Improvement of quality of life for patients and families.
- Handling of time-intensive family/patient/team meetings.
- Coordination of care.
- Support of patients and families.
- Specialty-level assistance to the attending physician.
- Support for attending physicians and discharge planning staff.
- Improvement in patient/family satisfaction.
- Improvement in nurse and physician satisfaction.

BECAUSE PALLIATIVE CARE has seen an increase in demand and become an expected part of the treatment regimen for many, it is imperative that teams of interdisciplinary professionals are educated to address the palliative care needs of patients and families. In addition, there is an increased need to offer outpatient palliative care services for individuals who prefer to remain at home or in other settings.¹⁶

With this comes the realization that each resident of Maryland must be aware of the importance of advanced care planning as well as palliative and hospice care options. The bioethical principle of patient autonomy states that a competent individual has the right to decide for or against any medical treatment.¹⁷ Individuals have the right to be informed to make decisions regarding their healthcare at all points in the cancer care trajectory. To be an informed consumer of healthcare, individuals must have a clear understanding of all treatment options, including palliative care in conjunction with curative therapy, as well as palliative and hospice care as the focus at end of life.

Key Stakeholders in Palliative and Hospice Care

For the purposes of this chapter, the following key stakeholders have been identified as important for creating a comprehensive palliative care system.

Patients, Families, and Communities

- **PATIENTS:** Individuals with a diagnosis of cancer at any phase of the illness experience.
- **FAMILY:** Any individual who provides direct or indirect support of a patient experiencing cancer.
- **COMMUNITY:** A group of interacting people living in a common location and who share common values or interests.

Healthcare Professionals and Associated Staff

- **HEALTHCARE PROFESSIONALS:** All members of the palliative care and hospice interdisciplinary team including physicians, nurses, social workers, psychologists, chaplains, pharmacists, physical or occupational therapists, as well as patients' oncologist or primary care physician.
- **ASSOCIATED STAFF:** All individuals involved in the caring process who offer direct or indirect support in the care of oncology patients and their families across all healthcare settings.

Institutions

ALL HEALTHCARE DELIVERY SYSTEMS that provide palliative or hospice care, such as medical centers, hospitals, rehabilitation hospitals, sub-acute and long-term care facilities, assisted-living facilities, hospices (inpatient, home, or residential), or related office/outpatient clinics.

Healthcare Policymakers, Legislators, and Payers

MARYLAND STATE AND CONGRESSIONAL LEGISLATORS, the Maryland executive branch of government, two key federal agencies, the Centers for Medicare and Medicaid (CMS) and the Centers for Disease Control and Prevention (CDC), insurers, philanthropists, as well as the business community, including employers and caregiver advocacy organizations.

A Blueprint for Success

THE GOAL OF IMPLEMENTATION of a blueprint for success for palliative and hospice care across the state of Maryland will necessitate the achievement by each of the stakeholder groups of what is termed the “4 A’s”: Awareness, Acknowledgement, Access, and Action.

- **AWARENESS** implies knowledge and appreciation gained through one’s perceptions or by means of information about palliative and hospice care.
- **ACKNOWLEDGMENT** is the recognition and acceptance of the value of palliative and hospice care.
- **ACCESS** is the right, privilege, or ability to make use of resources and information related to palliative and hospice care.
- **ACTION** is the development, implementation, and evaluation of initiatives to promote palliative and hospice care—which will lead to inclusion of palliative and hospice care into the standards of care and setting of future goals.

It is important that each of the identified stakeholder groups develops an awareness of palliative care, acknowledges its value, promotes access to quality palliative and hospice care, and takes action to implement a standard of practice in palliative and hospice care. Based on a review of the literature and collaborative efforts of the Maryland experts in the field of palliative care, strategies have been identified for each of the stakeholder groups in relation to the 4 A’s. These strategies serve as the cornerstones of the blueprint for success for palliative and hospice care for patients and families experiencing cancer in the state of Maryland.

Patients, Families, and Communities

THE CARE OF THE SERIOUSLY ILL AND DYING has always involved the relationship of patients, their families, and communities. However, in the past century, the care of seriously ill and dying individuals has shifted away from the family and community into hospitals due to the rapid development of life-prolonging technologies. These technologies include drugs, new procedures and medical devices, and improved imaging techniques. While the goal for some patients may be to prolong life at any cost, others may want their pain and other symptoms controlled to

FAST FACT The ultimate goal of palliative and hospice care is to improve overall quality of care for patients with serious illness and their families. Patients and families must be able to access these services in their communities.

have a better quality of life in their final months and days. Palliative and hospice care programs are models for high-quality care with valuable services to the sickest, most vulnerable individuals and their families.

In 2008, the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC) released a report card on palliative care. The report shows that the percentage of hospitals with 50 or more beds reporting a palliative care program almost doubled from 2000 to 2006.¹⁸ Despite this growth, many seriously ill individuals may not be aware of or may lack access to palliative care before they are eligible for hospice care.

Educating the community through public awareness campaigns on The Joint Commission’s (TJC) standards for institutions that seek a voluntary Palliative Care Accreditation and marketing the institutions/agencies that offer palliative and hospice services will increase public knowledge. It is also important that healthcare facilities have missions, visions, and philosophies of care that emphasize the importance of patient-centered care and teamwork.

The ultimate goal of palliative and hospice care is to improve the overall quality of care for patients with serious illness and their families. However, patients and families must be able to access these services in their community. Timely referrals to these services are affected by geographic availability, physicians’ reluctance to refer to hospice services, financial barriers such as lack of reimbursement, insufficient provider training, and patients and families being unaware of or unwilling to discuss palliative and hospice care options.¹⁹

Currently, patients and their families remain undereducated about advanced care planning, palliative, and hospice care.²⁰ This is attributed to the general cultural attitude in which death is rejected as an option and conversations about

FAST FACT The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care recommends that palliative and hospice care be provided by an interdisciplinary team of skilled palliative care professionals.

death and dying are uncomfortable for patients and their families. Work should be done to raise expectations about the education patients receive. Increased knowledge of palliative and hospice care may result in patient conversations with healthcare providers they might not have had otherwise.²¹ This awareness will empower the patient and family to take an active role in conversations about goals of treatment and expected outcomes, and to have a clearer understanding of options should treatment fail to cure or control the cancer. An integral part of these conversations should be the completion of advanced directive documents with the subsequent sharing of the documents with family as well as healthcare providers.

Evidence shows that cultural change is unlikely to happen without public demand for that change.²² Armed with the knowledge and experience of palliative care, individuals, families, and community can come together and take action to increase the availability and provision of such care. These open conversations will lead to supporting the creation of a healthcare environment where physical symptoms and emotional and spiritual needs are acknowledged and addressed in a holistic manner throughout the cancer trajectory. Increased awareness, improved communication, and the expectation to be involved in each decision regarding one's healthcare will ensure a better quality of life regardless of the quantity of that life.

Healthcare Professionals and Associated Staff

WITH THE RECOGNITION OF PALLIATIVE CARE as a subspecialty in both medicine and nursing, the challenge is to educate enough health professionals in palliative care to staff the rapid national increase in palliative care programs. Through programs such as the End of Life Nursing Education Consortium (ELNEC) and Education for Physicians in End of Life Care (EPEC), nurses, physicians, social workers, and other practitioners are being trained in pallia-

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tive care. Undergraduate programs in nursing, graduate programs in nursing and social work, and medical school programs are incorporating palliative care content into their curricula. Master's and post-master's certificate programs in nursing and social work are being offered in palliative care along with the development and implementation of interprofessional fellowship programs involving disciplines with interest in palliative care (medicine, nursing, psychology, social work, pharmacy, chaplaincy, occupational, and recreational therapy).

Collaboration across disciplines is a key concept in palliative and hospice care. The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care recommends that palliative and hospice care be provided by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).²³

Recognizing the opportunity that interdisciplinary care provides, it will become important to provide interdisciplinary education to support the integration of palliative care and optimize interdisciplinary work to the benefit of all involved. Interdisciplinary education engages all health disciplines in learning together and more importantly in learning how to work together.²⁴ Developing a broader understanding of different viewpoints/roles and learning tolerance, cooperation, and functional communication are fostered by interdisciplinary study.²⁵ Clinical competencies address the ethical and cultural contexts of disciplines and lead to the provision of quality care.²⁶

The American Association of Colleges of Nursing (AACN) and the Pew Health Professions have both endorsed an interdisciplinary approach to education.^{27,28} Through education, health professionals from all disciplines will develop the competencies to increase their communication skills related to palliative care in conversations with patients and families, contribute to excellence in clinical practice by sharing their knowledge and expertise with other health professionals through publications and presentations, and promote the specialty through participation in media and marketing campaigns. By actively

participating in palliative care educational initiatives, practitioners will promote their ongoing professional development in palliative care and serve as mentors to those who are entering the profession. These practitioners must ascertain patient's values, explore potential options for goals of care, identify available resources, and assist with advanced care planning.

Through acknowledging the value, healthcare professionals will promote access to palliative care and increase their referral rates to both palliative care and hospice. The expectation is that healthcare professionals will incorporate the National Quality Forum Preferred Practices of Palliative Care as a standard of care within institutions. Research is needed to measure interdisciplinary education and care outcomes alike as part of healthcare quality improvement and system reform.²⁹

Institutions

PALLIATIVE CARE INITIATIVES require not only clinical champions and administrative champions at the local level, but executive leaders at the corporate or systems level.³⁰ Administrators must be aware of the national initiatives related to palliative care and acknowledge its value to quality patient care.³¹ This awareness may then lead to the incorporation of palliative care goals and tactics into the institution's strategic plan. Administrators must also budget substantial resources for educational outreach to insure appropriate utilization of palliative care and to convey the message of its value in relation to cost savings, cost avoidance, quality care, and patient and family satisfaction. Utilizing philanthropic and other contributions can also add to a revenue base for hiring a skilled and credentialed team of interdisciplinary professionals.

The State of Maryland Office of the Attorney General's "Workgroup Report on Hospice Care, Palliative Care and End of Life Counseling" emphasizes that healthcare facilities should be encouraged to develop systems to utilize health professionals currently trained in palliative and hospice care. Of extreme importance is the hiring of interprofessional palliative care practitioners to staff such services and promote the coordination of care across healthcare settings.³² Facilities should be encouraged to expand educational

opportunities for all healthcare professionals at various levels and to monitor the frequency and quality of care provided by practitioners.³³

Institutionally, the work is to connect people to each other, to the data, to the business case, mission, and quality case for palliative care.³⁴ The National Quality Forum Consensus Recommendations for operational features of palliative care programs include the importance of

- **ALIGNING THE MISSION** of the palliative care program with the mission of the institution.
- **OFFERING VALUED SERVICES** by inpatient consultation and outpatient practice.
- **INSURING THE AVAILABILITY** of both routine and emergency services.
- **MEASURING** patient/family and institutional outcomes.
- **INCORPORATING** quality improvement.
- **FUNDING** the marketing of palliative services.

Institutions with case management and patient navigator programs are providing some of the much-needed care coordination for cancer patients. The need for patient navigation is described in a report by the President's Cancer Panel, which recommends such programs to help communities coordinate, promote, and support community-based programs.³⁵ Patient navigation programs are found within some hospital systems to help patients navigate their cancer care while under treatment.³⁶ There are also case management programs within insurance companies that are working to provide holistic care coordination, education, navigation, and facilitation of the needs of a patient and family as the patient goes along the trajectory of the cancer experience.³⁷

Healthcare Legislators, Policymakers, and Payers

STATE AND LOCAL GOVERNMENTS can facilitate changes in health policy, quality standards, and reimbursement incentives to provide for ongoing education and training in palliative care and to develop a Bill of Rights related to palliative and hospice care.

The State of Maryland Office of the Attorney General's "Workgroup Report on Hospice Care, Palliative Care and End of Life Counseling" identified three categories of barriers Marylanders face in getting access to quality palliative and hospice care. Barriers included lack of information about

the tradeoffs of such care, cost, and administrative hurdles.³⁸ The identified barriers and set of policy actions recommended to reduce them were not only tailored to boost access to palliative care for Marylanders, but consistent with findings about barriers and remedial policy actions nationwide.³⁹

Additionally, state governments can effect change by promoting the development of a Center for Excellence in Palliative Care. Center resources and support would be available to remote or sole community provider hospitals, as well as 24 hour urgent care centers and clinics where continuity of care is challenged and end-of-life care planning may not occur. Legislatures can advocate for initiatives addressing quality improvement studies that track requests for palliative care consults, patient and family outcomes, healthcare professional outcomes, and financial and economic outcomes.

Achieving the goal of access to high-quality palliative care for all Marylanders and all Americans who need it regardless of geography, diagnosis, prognosis, state of illness, care setting, family situation, or social class will require government and regulatory policy to bring palliative care innovation to scale.⁴⁰ Policy solutions will range from the funding of career development awards in palliative medicine and nursing to lifting the cap on graduate medical education dollars for medical fellowships, increasing the National Institutes of Health funding for palliative care research, and addressing the more complex issues of payment reform and reimbursement for palliative care services.⁴¹

A specific advocacy and legislative agenda would include the integration of palliative care and hospice care. The legislative agenda should address relevant healthcare reform initiatives such as the comparative effectiveness of palliative care and hospice with traditional hospital care, bundled payments, and funding of demonstration projects that test the integration of comprehensive palliative care in the care of patients with complex medical needs.⁴² Healthcare policymakers should be encouraged to implement programs that will improve the quality of care while slowing the growth of total healthcare spending in the nation: it is this platform that defines palliative care and its goals.⁴³

Meier and Beresford (2008) sound the call to the palliative care community to get involved in issues at the state level, to build and identify a state’s organizational infrastructure for palliative care, and to respond quickly to public policy issues—given that palliative care practitioners “have an important stake in understanding the legislative and regulatory processes and influencing how these issues get addressed” (p.1070).⁴⁴

The interface of energies and visions among healthcare professionals, institutions, healthcare policymakers, legislators, and payers is critical to create much-needed reform as well as the crafting of policies that will promote the well being of patients, families, and communities facing serious, life-threatening illness. It is this interface that provides not only an informed perspective but can achieve a “meeting of the minds” to insure high-quality care and continuous care.

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GOALS - OBJECTIVES - STRATEGIES

A more detailed version of the Goals/Objectives/Strategies can be found on the Palliative and Hospice Care page of the Maryland Cancer Plan Web site: www.marylandcancerplan.org.

GOAL

Implement a blueprint for success for palliative and hospice care for patients and families experiencing cancer in the state of Maryland.

OBJECTIVE 1 AWARENESS

By 2015, develop an awareness campaign to educate Maryland citizens about palliative and hospice care within 50% of Maryland jurisdictions.

STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** seek information on palliative and hospice care and advanced care planning from their healthcare providers, public library, national and local cancer agencies, and local health department.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** increase communication related to palliative care issues in patient conversations, healthcare publications, and media/marketing.
- 3 **INSTITUTIONS:** initiate palliative care activities with the goal of obtaining buy-in from various constituencies.
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** conduct an internal education effort on strategies to reduce barriers that Maryland residents face in regard to quality palliative and hospice care. The education effort should include widespread distribution, discussion, and the development of an action plan based on:
 - The 2009 “Workgroup Report on Hospice Care, Palliative Care and End of Life Counseling,” released by the Maryland Attorney General’s Counsel for Health Decisions Policy workgroup, and
 - “Reports of the Maryland State Advisory Council on Quality of Care at the End Life.”

OBJECTIVE 2 ACKNOWLEDGING THE VALUE

By 2015, increase the participation in and support of palliative and hospice care initiatives by stakeholders as outlined in the strategies.

STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** participate in campaigns that support/promote palliative and hospice care and advanced care planning.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** actively participate in palliative education and palliative care initiatives as demonstrated by attendance at national conferences, increase in certification and credentialing rates, and referral to palliative care services and hospice care.
- 3 **INSTITUTIONS:** develop a strategic plan that incorporates goals and related tactics to institutionalize palliative care as it relates to ongoing professional education, implementing and maintaining supportive services for patient/families, supporting research and evidence-based practice, and driving healthcare policy and legislative initiatives that promote palliative care.
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** conduct outreach efforts via email, town halls, and focus groups to educate constituents about the knowledge, financial, and administrative barriers Maryland cancer patients and their families face in regard to palliative and hospice care and get their input on options to reduce them.

GOALS - OBJECTIVES - STRATEGIES

OBJECTIVE 3 ACCESS

By 2015, increase access to palliative and hospice care services in Maryland.

STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** request access to palliative and hospice services.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** develop and implement educational programs (formal and informal) related to palliative and hospice care.
- 3 **INSTITUTIONS:**
 - Develop a mechanism to track the percentage of palliative care consultations for hospital patients admitted with cancer, and
 - Ensure clinical support through hiring a skilled and credentialed/certified team of interdisciplinary palliative care professionals and associated support staff in order to implement a palliative care consult service or other delivery models (such as an inpatient unit, outpatient clinic, homecare program, and/or establishing partnerships with community hospices).
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** explore legislative options for expanding access to and payment for palliative and hospice care, building on best practices.

OBJECTIVE 4 ACTION

By 2015, stakeholders will take ownership of the Blueprint for Success and act on 70% of the strategies recommended for each stakeholder group.

STRATEGIES (BY STAKEHOLDER GROUP)

- 1 **PATIENTS/FAMILIES/COMMUNITIES:** advocate for effective and compassionate palliative care across healthcare settings to insure that the goals of care are achieved.
- 2 **HEALTHCARE PROFESSIONALS AND ASSOCIATED STAFF:** incorporate the National Quality Forum Preferred Practices of Palliative Care as a standard of care within the institution.
- 3 **INSTITUTIONS:** initiate quality improvement studies to evaluate the provision of quality palliative care by tracking:
 - Requests for palliative care consults.
 - Patient/family and community outcomes.
 - Healthcare professional outcomes.
 - Economic outcomes.
- 4 **HEALTHCARE LEGISLATORS/POLICYMAKERS/PAYERS:** support pilot programs that test:
 - The feasibility and impact of training lay workers to serve as palliative and hospice care counseling coaches and navigators.
 - Reimbursement models for providing end-of-life care counseling.
 - The impact of innovative clinical-financial models of palliative and hospice care for cancer patients and their families designed to reduce knowledge, financial, and administrative barriers to their use.

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