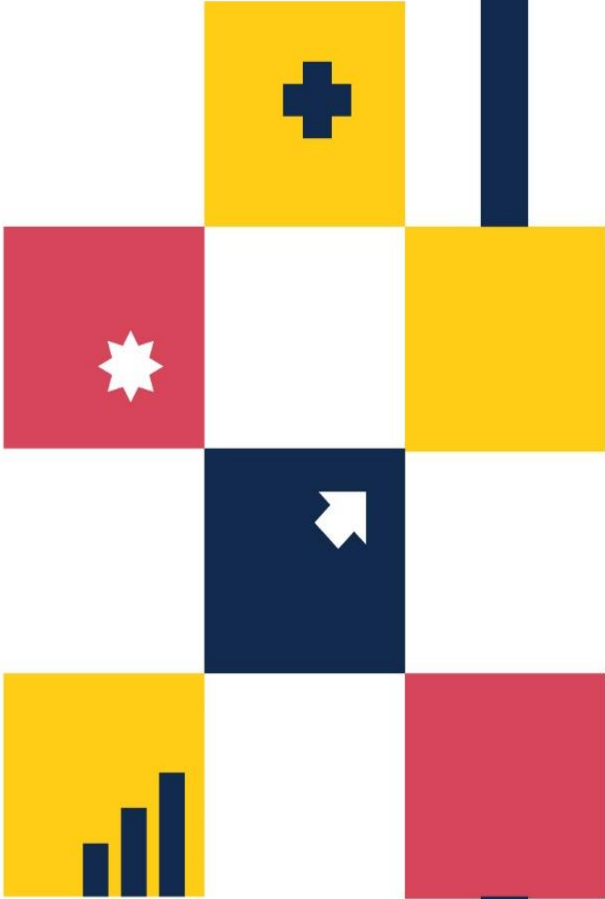


House Bill 378 (2022): Current Status of Palliative Care Services in Maryland

Interim Report to the
Legislature
July 2023

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This report was developed in collaboration with Swain Eng and Associates, L.L.C. (dba SEA Healthcare) (www.swainengassociates.com) with data analysis assistance from Tenacity Solutions.

Background

House Bill 378, passed during the 2022 Maryland Legislative session, and codified as Chapter 301, Acts of 2022, requires the Maryland Health Care Commission (MHCC) to convene a workgroup to “study palliative care services and make recommendations to improve palliative care services in the state.”¹

Specific requirements for this workgroup under the Scope of Work include examining:

- State of palliative care services offered in the state;
- Capacity of palliative care providers to provide services;
- Geographic areas where significant gaps in palliative care services may exist;
- Opportunities to collaborate with key stakeholders to develop a plan for improving and expanding the provision of high-quality palliative care medicine and services;
- Feasibility of financial support for long term expansion of palliative care, including insurance coverage;
- Plan for ongoing data collection for purposes of monitoring and improvement of palliative care services;
- Engagement strategies for educating the public about palliative care to empower individuals to make informed decisions about an individual’s preferred care when faced with serious illness; and
- Other strategies that would improve palliative care services.

Palliative Care Services Workgroup²

The multi-disciplinary Palliative Care Services Workgroup was formed in the Fall of 2022 and included representatives from the following organizations and providers:

- Maryland Hospital Association
- Hospice
- Nursing Home
- Home Health Agency
- State Advisory Council on Quality Care at End of Life
- Nurse Practitioner/Consultant
- Hospice & Palliative Care Network of Maryland
- AARP Representative
- Maryland Department of Aging
- Payors: Medicare, Medicaid, League of Life Insurers, and CareFirst

¹ HB 378 (2022 Legislative Session) see Appendix A.

² Palliative Care Workgroup Full Roster see Appendix B.

Palliative Care Workgroup Meeting Objectives³

The objectives encompassed in the Workgroup meetings to date were as follows:

- ▶ **Meeting 1 (09/21/2022):**
 - Selected CAPC definition of palliative care
 - Selected four care settings: hospitals, nursing homes, home health agencies, hospices
 - Agreed on Statewide Survey
- ▶ **Meeting 2 (11/14/2022):**
 - Selected Colorado Survey (phone) edited for Maryland use
 - Payor representatives presented challenges to financing palliative care
- ▶ **Meeting 3 (01/09/2023):**
 - Bid Board discussed
 - Consumer representatives presented their views on Palliative Care Services
- ▶ **Meeting 4 (05/23/2023):**
 - Reviewed initial data from web-based Statewide Survey
 - Discussion of emerging themes
- ▶ **Meeting 5 (06/28/2023):**
 - Review of additional finding from web-based Statewide Survey
 - Review of draft recommendations and Outline of Interim Report

Defining Palliative Care

Research on palliative care is challenged by the fact that there is no consensus on what palliative care is and how it is defined. Following a thorough examination of the literature, the MHCC staff assembled the Palliative Care Services Workgroup to evaluate and deliberate upon diverse definitions of palliative care. After engaging in discussions, the Workgroup successfully reached a consensus on adopting the palliative care definition from The Center to Advance Palliative Care (CAPC)⁴:

“Palliative Care is specialized medical care for people living with serious illness. This type of care is focused on providing relief from the symptoms and stress of illness. The goal is to improve quality of life for both the patient and family. Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative

³ Palliative Care Workgroup Meeting Summaries see Appendix C.

⁴ Center to Advance Palliative Care (2022) What is Palliative Care? Retrieved September 12, 2022, from: <https://www.capc.org/about/palliative-care/>

care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and any stage of a serious illness, and it can be provided along with curative treatment.”

The CAPC definition of palliative care, widely recognized in the palliative care industry, served as a robust and well-established operational framework for the Maryland Statewide Palliative Care Survey. This definition played a pivotal role in guiding the survey's design and structure, ensuring alignment with industry standards and best practices to assess formal palliative care programs. Moreover, the CAPC definition influenced the literature search conducted during the environmental scan, directing the focus towards relevant research and resources that align with the recognized principles and components of palliative care. By utilizing this widely accepted definition, the survey and environmental scan were able to capture valuable insights and data that contribute to the advancement and improvement of palliative care practices in Maryland. See Appendix D for Statewide Palliative Care Survey.

Statewide Survey Process

Selection of the Consulting Firm

SEA Healthcare was chosen through a contracting process to conduct an extensive study on palliative care programs in Maryland. To aid in data analysis, they enlisted the support of Tenacity Solutions as an analysis subcontractor. The Maryland Statewide Palliative Care Survey encompassed data collection via a web-based survey, phone, and email, specifically targeting recognized Maryland hospitals, nursing homes, hospices, home health agencies, and other palliative care community providers. The collected data underwent analysis to derive distinct insights categorized by provider type, jurisdiction, and at the statewide level. The analysis aimed to identify gaps in palliative care services, including those related to geographical access, financial access, and staffing resources. Additionally, the study sought to identify challenges and obstacles both statewide and by jurisdiction, along with recommended strategies for achieving the goals set by the legislation.

Survey Approach and Methodology

As part of the survey administration process, several steps were taken to ensure the successful implementation of the study. First, the Colorado Palliative Care telephone survey was reconfigured into a web-based survey using Survey Monkey, allowing for greater accessibility and ease of participation. Second, to ensure the effectiveness of the survey, beta testing was conducted with the assistance of members of the Palliative Care

Services Workgroup, representing volunteers from Maryland healthcare associations, groups, and professionals, who provided valuable feedback and suggestions for improvement. Furthermore, to ensure broad participation from healthcare organizations, proactive measures were taken to update contact lists of hospitals, nursing homes, hospices, and home health agencies. Collaborations were established with Maryland healthcare associations to facilitate introductions and encourage survey participation among their member organizations. Working closely with the Workgroup members and relevant associations, a comprehensive list of contacts was compiled and continually updated throughout the survey data collection process.

The survey was then distributed to the identified target groups after accounting for removing duplicate entries, adding missing organizations and removing closed programs. For hospitals, the survey was sent to 46 institutions. Similarly, the survey was sent to 227 nursing homes. For hospices, the survey was distributed to 27 organizations. Lastly, the survey was sent to 56 home health agencies. These steps were taken to ensure that a comprehensive and representative sample of healthcare organizations was included in the survey process.

The data collection for the survey utilized a multifaceted approach to maximize participation. Initially, each organization was contacted through Survey Monkey emails, providing comprehensive information and instructions to facilitate their survey participation. Subsequently, multiple follow-up emails were sent to designated contacts within the organizations to encourage prompt response and enhance participation rates. Moreover, in addition to emails, non-responsive organizations were proactively contacted through multiple follow-up phone calls, with the aim of capturing data from as many organizations as possible.

The data collection period began on February 22, 2023, and was expected to close on March 24, 2023. However, recognizing the importance of capturing additional responses, the data collection period was extended until April 14, 2023. A few final surveys were submitted for manual data entry on April 30, 2023, to include any remaining organizational data that was received after the extended deadline. This comprehensive data collection methodology and extended period allowed for a thorough and inclusive representation of the survey respondents' perspectives and insights.

Data Cleaning

To filter survey respondents who responded to the survey, met the eligibility criteria, and completed the survey question, we utilized the following steps:

1. Identify the eligibility criteria: Define the specific conditions or requirements that respondents must meet to be considered eligible.
 - a. Are you authorized to answer detailed questions about your organization's palliative care program and services offered? (Response must be "yes" to be eligible)
 - b. This survey is focused on organizations that have a **formal** palliative care program. For the purposes of this survey, we used the Center to Advance Palliative Care's (CAPC) definition of a formal palliative care program. "Palliative care is specialized medical care for people living with serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and family. Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage of a serious illness, and it can be provided along with curative treatment."-[CAPC 2023](#)
 - c. Does your organization have a Formal Palliative Care Program as defined by the CAPC definition that either directly or by contractual arrangement provides palliative care services to your patients/clients/residents? (Response must be "yes" to be eligible)
2. Review survey responses: Analyze the survey responses to identify respondents who meet the eligibility criteria. Each respondent's data should include information related to the eligibility criteria, which was used to filter the responses.
3. Check for completion: Within the survey responses, locate the question or questions that need to be completed to consider a response as valid. Ensure that the respondents have provided answers to those particular questions.
4. Apply filters: Apply filters or queries to the survey response data to extract the desired subset of respondents who meet all the criteria. Subsets included organization type, jurisdiction, and region.
5. Review the filtered respondents: Once the filters are applied, review the resulting list of respondents who responded to the survey, met the eligibility criteria, and completed the survey question(s).

The survey results will be included in the Final Report to the Legislature. In addition, a Palliative Care Provider Directory will be developed as a resource for providers and the public on the availability of palliative care service providers.

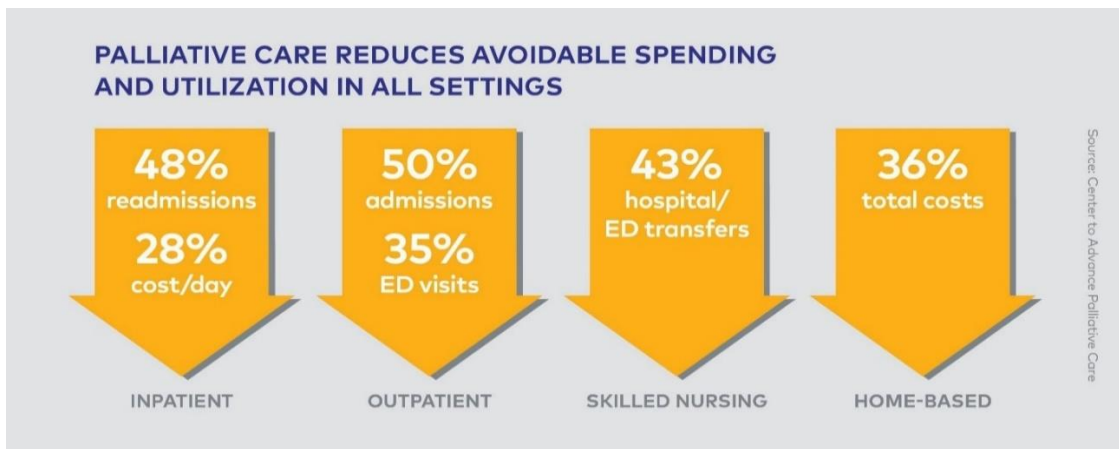
Importance of Palliative Care

Palliative care specialists play a vital role in enhancing the quality of life for patients with complex needs. By working collaboratively with primary care physicians, the palliative care team offers a range of essential services that address the unique challenges faced by these patients. This section examines the benefits of integrating palliative care specialists into healthcare settings and highlights the positive outcomes associated with their involvement.

Benefits of Palliative Care

1. **Dedicated Time for Family Meetings and Counseling:** Palliative care specialists allocate sufficient time to conduct intensive family meetings and provide patient and family counseling. This allows for meaningful discussions about the patient's condition, prognosis, and treatment options. By fostering open and compassionate communication, the care team ensures that care aligns with the patient's goals and priorities, promoting shared decision-making.
2. **Skilled Communication for Future Expectations:** A key aspect of palliative care is skilled communication that prepares patients and families for what to expect in the future. Through clear and empathetic discussions, palliative care specialists help individuals understand their prognosis, potential challenges, and available support resources. By aligning care with the patient's values, this proactive approach ensures that treatment decisions are well-informed and reflective of the patient's preferences.
3. **Expert Symptom Management:** Palliative care specialists possess expertise in managing complex physical and emotional symptoms. They address a wide range of issues, including pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite, and difficulty sleeping. By implementing tailored symptom management strategies, the palliative care team improves patients' comfort, well-being, and overall quality of life.
4. **Coordination and Communication of Care Plans:** Another crucial role of palliative care specialists is coordinating and communicating care plans among all providers and across various healthcare settings. This comprehensive approach ensures seamless transitions and minimizes gaps in care. By facilitating effective collaboration among healthcare professionals, the palliative care team enhances care continuity and optimizes patient outcomes.

Many of the studies on palliative care indicate cost savings as a result of reduced hospital admissions and readmissions as illustrated below:



Source: CAPC: capc.org/the-case-for-palliative-care/

Numerous studies have consistently demonstrated the significant positive impact of palliative care on patient quality of life. By addressing physical symptoms, providing emotional support, and promoting effective communication, palliative care improves overall well-being and reduces symptom burden. This focus on enhancing quality of life not only benefits patients but also contributes to reducing stress and trauma for their families during encounters with the healthcare system.

State of Palliative Care in the United States

The United States currently has a substantial population of individuals living with serious illnesses, estimated to be at least 12 million adults and 400,000 children.⁵ This includes individuals with conditions such as metastatic cancer, advanced dementia, heart failure, and congenital illnesses. Projections indicate that this number is anticipated to grow significantly in the coming two decades.

⁵ Hayes SL, Salzberg CA, McCarthy D, et al. (2016) High-need, high-cost patients: who are they and how do they use health care? A population-based comparison of demographics, health care use, and expenditures. Issue Brief. *Commonwealth Fund*. 26:1–14. Retrieved April 5, 2023 from:

www.commonwealthfund.org/publications/issue-briefs/2016/aug/high-need-high-cost-patients-who-are-they-and-how-do-they-use.

Institute of Medicine. (2003) *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, DC: The National Academies Press; doi: 10.17226/10390

By the year 2035, the population of individuals aged 65 and above, with 81% of them living with multiple chronic conditions, is projected to reach nearly seventy-eight million. This will surpass the number of individuals aged 18 and below, as well as the number of women aged 18 to 55, who have traditionally been part of the caregiver workforce.

The landmark 2014 report "Dying in America" by the Institute of Medicine unequivocally stated that all individuals with advanced serious illness should have access to palliative care specialists.⁶ However, the stark reality is that the United States is currently facing a dire shortage of trained palliative care specialists, which not only fails to meet the current needs but also leaves us ill-prepared for the escalating demands in the future.

According to a recent report by The Commonwealth Fund titled "Being Seriously Ill in America Today," individuals with the greatest healthcare needs are consistently receiving poor-value care.⁷ The report highlights several concerning findings:

- **Patient Experience:** 22% of seriously ill individuals reported that hospital staff were unresponsive to their needs, 23% received conflicting information from different healthcare professionals, 21% would not recommend their hospital to others with the same illness, and less than 50% were asked about their personal preferences in critical situations.
- **Healthcare Costs:** 37% of respondents depleted most or all of their savings to deal with their health condition, despite 91% having health insurance. Additionally, 23% reported being unable to afford basic necessities such as food, heating, or housing.
- **Caregiver Distress:** Over one-third of those who relied on family caregivers experienced strains and burdens, including emotional and physical stress, financial difficulties, and poorer caregiver health.

These findings indicate significant gaps in the quality and affordability of care for individuals with serious illnesses. It highlights the need for improvements in patient experience, better management of healthcare costs, and increased support for caregivers. Addressing these issues is crucial to ensure that seriously ill individuals receive the high-quality care and support they require.

⁶ Institute of Medicine. (2015). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/18748>.

⁷ The Commonwealth Fund, The New York Times, Harvard T.H. Chan School of Public Health. (2018) *Being seriously ill in America today*. Retrieved June 10, 2023, from: <https://cdn1.sph.harvard.edu/wp-content/uploads/sites/94/2018/10/CMWF-NYT-HSPHSeriously-Ill-Poll-Report.pdf>.

Federal Legislation (2020-2023)

During the last three years, both the Senate and the House have witnessed the introduction of legislation specifically focused on palliative care. Moreover, additional bills have been presented that address palliative care services concerning cancer, dementia, other serious illnesses, older adults, workforce development, care models, education, and training.

- **Senate Bill 1845 (2023-2024)** -The bill would amend title XI of the Social Security Act to provide for the testing of a community-based palliative care model. The bill was introduced June 7, 2023 and referred to Committee on Finance.
- **Senate Bill 2565 (2023-24)**-Expanding Access to Palliative Care Act. This bill was introduced on June 8, 2023, and was referred to Committee on Finance. If passed, the bill would require the Center for Medicare and Medicaid Innovation (CMMI) to develop a community-based palliative care (CBPC) demonstration. The model would provide essential interdisciplinary care to people with serious illness in their home and lead to improved quality and cost outcomes.
 - **Senate Bill 2565 (2021-22)** – (Earlier version of the 2023 legislation introduced with the same number SB 2565). This bill requires the Center for Medicare and Medicaid Innovation (CMMI) to test a model that provides community-based palliative care and care coordination for high-risk Medicare beneficiaries and that may replace the Medicare Care Choices Model (set to expire on December 31, 2021).
- **Sente Bill 2117 (2023-2024)** -The bill would allow participants in the National Health Service Corps to defer their obligated service in order to receive training in palliative care services. The bill was introduced June 22, 2023, and referred to Health, Education, Labor, and Pensions Committee.
- **H.R.4363** – This bill addresses the health of cancer survivors and unmet needs that survivors face through the entire continuum of care from diagnosis through active treatment and posttreatment, in order to improve survivorship, treatment, transition to recovery and beyond, quality of life and palliative care... and for other purposes. The bill was introduced June 23, 2023, and referred to the Committee on Energy and Commerce, and in addition to the Committees on Ways and Means, and Education and the Workforce, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned.
- **HR. 1493 (2023-2024)** - HCBS Access Act. This bill would amend title XIX of the Social Security Act to require coverage of, and expand access to, home and community-based services under the Medicaid program; to award grants for the

creation, recruitment, training and education, retention, and advancement of the direct care workforce and to award grants to support family caregivers; and for other purposes. The bill was introduced on March 17, 2023, and referred to the Subcommittee on Health.

- **Senate Bill 4260 (2021-22)** - Palliative Care and Hospice Education and Training Act (PCHETA): This bill mandates that the Department of Health and Human Services (HHS) undertake various initiatives to enhance palliative care training. The bill entails providing support for Palliative Care and Hospice Education Centers to enhance the training of healthcare professionals in palliative care and establish traineeships for individuals pursuing advanced education in nursing, social work, or physician-assistant studies in palliative care. HHS is also empowered to offer support to medical schools, teaching hospitals, and graduate medical-education programs for training physicians who intend to teach palliative medicine. Additionally, HHS is required to provide career development awards, support entities operating Palliative Care and Hospice Education Centers, assist individuals pursuing advanced degrees in palliative care, and grant funds to nursing programs for palliative care training. Furthermore, the bill directs the Agency for Healthcare Research and Quality to conduct a national education and awareness campaign to educate patients, families, and healthcare professionals about the benefits of palliative care. Lastly, the National Institutes of Health is tasked with expanding national research programs in palliative care. This bill was introduced to the Senate on May 19, 2022. It was then referred to Senate Health, Education, Labor, and Pensions Committee.
 - **H.R. 647 (2019-2020)** - Palliative Care and Hospice Education and Training Act passed on 10/29/2019. This bill requires the Department of Health and Human Services (HHS) to take a series of actions relating to palliative-care training.
- **S.Res.849 (2021-2022)** - A resolution designating November 2022 as "National Hospice and Palliative Care Month". The resolution was submitted in the Senate, considered, and agreed to without amendment and with a preamble by Unanimous Consent on November 28, 2022.

CAPC State-by-State Report Card

According to the latest data available from 2019 CAPC State-by-State Report Card, the presence of palliative care teams in hospitals with fifty or more beds has increased

nationally to 72%.⁸ This represents a notable rise from 67% in 2015 and a significant growth compared to only 7% in 2001. These hospitals now cater to 87% of all patients admitted to hospitals in the United States, showing an increase from 82% in 2015. Ninety-four percent of U.S. hospitals with more than 300 beds now have a palliative care team, compared to 62% of hospitals with fifty to 299 beds.

However, regional disparities persist, with the highest concentration of palliative care teams observed in New England and the lowest in the south-central states. Notably, large nonprofit hospitals located in urban centers continue to be the primary institutions offering access to palliative care teams. Palliative care access in rural America continues to be restricted, with the majority of palliative care services concentrated in urban areas. A staggering 90% of hospitals offering palliative care are located in urban settings, while only 17% of rural hospitals with fifty or more beds have reported the presence of palliative care programs.

Trends in Palliative Care

Palliative care services are experiencing notable trends in recent years. There is increasing availability and acceptance, expanding beyond cancer diagnoses to include other serious illnesses. Integration with primary care, technology and innovation, patient and family-centered care, and a team-based approach are all shaping the delivery of palliative care. These trends reflect the evolving landscape and highlight the importance of comprehensive, patient-centered support.

1. **Increasing availability and acceptance:** Palliative care services have become more widely available in recent years, and there has been an increasing acceptance of the importance of palliative care in the medical community. More hospitals and healthcare systems are offering palliative care services to their patients.
2. **Expansion to non-cancer diagnoses:** While palliative care was originally developed, as was hospice care, for patients with terminal advanced cancer, it is increasingly being used to manage symptoms and improve quality of life for patients with other serious illnesses, such as heart failure, dementia, and chronic obstructive pulmonary disease (COPD).

⁸ Center to Advance Palliative Care. (2019) 2019 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals for additional details on data sources and methods for hospital palliative care. Retrieved June 5, 2023, from: <https://reportcard.capc.org>

3. **Integration with primary care:** Palliative care is increasingly being integrated with primary care, with palliative care specialists working closely with primary care providers to provide a comprehensive approach to patient care.
4. **Technology and innovation:** Technology and innovation are playing an increasing role in palliative care, with telemedicine and remote monitoring allowing patients to receive palliative care services in their homes.
5. **Focus on patient and family-centered care:** Palliative care services are increasingly focusing on providing patient and family-centered care, with a focus on addressing the physical, emotional, and spiritual needs of patients and their families.
6. **Team-based care:** Palliative care is typically delivered by a team of healthcare providers, including physicians, nurses, social workers, and chaplains. There is a growing recognition of the importance of team-based care in delivering high-quality palliative care services.

Integrating Palliative Care into Primary Care and Specialty Care

Palliative care encompasses the entire health care continuum, extending beyond the boundaries of hospitals. While many hospitals have established palliative care programs and most research has focused on inpatient settings, it is crucial to expand palliative care further into the community. This expansion requires a collaborative effort among palliative care specialists, primary care providers (PCPs), and other specialty providers.

Expanding palliative care into the community is a pivotal step in meeting the comprehensive needs of patients and families facing serious illness. By delivering palliative care services in familiar and comfortable surroundings, patients can experience enhanced stability, continuity, and an improved quality of life, aligning with their preferences for care.

Collaboration among palliative care specialists, PCPs, and other specialty clinicians plays a vital role in community-based palliative care. Through this collaboration, healthcare professionals can ensure effective care coordination and seamlessly integrate palliative care principles into the overall management of a patient's health. This collaborative approach addresses the comprehensive needs of patients, including symptom management, advanced care planning, psychosocial support, and spiritual care.⁹

⁹ Reymond, L., Parker, G., Gilles, L., & Cooper, K. (2018). Home-based palliative care. *Australian Journal of General Practice*, 47(11), 747–752. <https://doi.org/10.31128/AJGP-06-18-4607>

Moreover, expanding palliative care into the community holds the potential to reduce healthcare disparities by reaching underserved populations who face barriers in accessing hospital-based care. By bringing palliative care services closer to these communities, equitable access to palliative care can be improved, promoting a more patient-centered and equitable healthcare system.¹⁰

Current efforts are underway to expand the provision of palliative care services by PCPs to their patients with serious illnesses. This growing trend reflects the recognition among PCPs of the importance of care coordination, advanced care planning, and person-centered care in enhancing the overall quality of care.¹¹ PCPs are uniquely positioned to address the initial palliative care needs of their patients and families, further emphasizing the value of their involvement in the palliative care continuum.¹²

Community-Based Palliative Care

Community settings encompass a range of locations such as office practices, medical clinics, long-term care facilities, and patients' homes. Multiple studies demonstrate that the implementation of community-based palliative care leads to reductions in hospital and emergency department visits, decreased acute care expenditures, enhanced care continuity, improved quality of life, and better survival outcomes.

In 2016, the Center to Advance Palliative Care (CAPC) initiated a three-year project to identify community palliative care programs across the country.¹³ Health care organizations offering community palliative care were invited to participate by completing an online survey. They concluded that:

- Community palliative care programs are distributed fairly evenly between hospitals and hospices, which collectively account for two-thirds of all identified programs. The remaining one-third is operated by home health agencies, long-term care facilities, and office practices or clinics.

¹⁰ Mayeda, D. P., & Ward, K. T. (2019). Methods for overcoming barriers in palliative care for ethnic/racial minorities: a systematic review. *Palliative & supportive care*, 17(6), 697–706. <https://doi.org/10.1017/S1478951519000403>

¹¹ Roth, A. R., & Canedo, A. R. (2019). Introduction to Hospice and Palliative Care. *Primary Care*, 46(3), 287–302. <https://doi.org/10.1016/j.pop.2019.04.001>

¹² California Health Foundation. (2017). Weaving Palliative Care into Primary Care: A Guide for Community Health Centers. Retrieved June 1, 2023, from <https://www.chcf.org/wp-content/uploads/2017/12/PDF-WeavingPalliativeCarePrimaryCare.pdf>

¹³ CAPC. (2019) Mapping Community Palliative Care-A Snapshot. Retrieved May 26, 2023, from: <http://capc.org/documents/download/700/>

- Two-thirds of programs provide in-home palliative care. Within this group, 49% of the programs are operated by hospices, while hospitals operate 23%, home health agencies operate 15%, office practices or clinics operate 12%, and less than 1% are operated by long-term care facilities.
- Almost half of community programs (46%) provide palliative care services in an office practice or clinic setting.
- The majority of community programs treat adult patients only. Few community palliative care programs serve only children.

State of Palliative Care in Maryland

Maryland is actively engaged in various initiatives related to palliative care. Notably, hospital-based palliative care serves as a vital component in delivering high-quality support and improving the quality of life for individuals confronting serious illnesses within the state. Reports from the Center to Advance Palliative Care (CAPC) and the Coalition to Transform Advanced Care (C-TAC) shed light on the status of hospital palliative care in Maryland. This section aims to explore the present state of palliative care in Maryland, analyzing essential metrics, available resources, and ongoing initiatives that collectively contribute to the provision of comprehensive and superior care.

CAPC State Report Card for Palliative Care-Maryland

The [2019 CAPC State-by-State Report](#) provides information about hospital palliative access by state with supporting resources. Palliative care services in U.S. hospitals exhibit significant variability across states and regions. A comparative analysis, presented in the table, illustrates the availability of palliative care in Maryland in relation to regional and national averages, categorized by hospital size.¹⁴ Maryland scored an A on this measure. The data reveals that a majority of large hospitals, defined as those with 300 or more beds, currently offer palliative care services. However, smaller hospitals face resource limitations, resulting in a lower percentage of them being able to meet the standard of having a comprehensive palliative care interdisciplinary team.¹⁵

¹⁴ Center to Advance Palliative Care analysis. (2019) 2019 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals for additional details on data sources and methods for hospital palliative care. Retrieved June 5, 2023, from: <https://reportcard.capc.org>

¹⁵ National Consensus Project for Quality Palliative Care.(2018) Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; Retrieved January 31, 2023, from: <https://www.nationalcoalitionhpc.org/ncp>

Table. CAPC Hospital Palliative Care Report Card-Maryland (2019)

Location	2019 Grade*	<50 beds	50-150 beds	151-299 beds	300+ beds
Maryland	95% A	66.7%	92.9%	93.3%	100.0%
South-Atlantic Region	70.5% B	34.4%	52.8%	69.6%	93.2%
National	71.5% B	36.3%	51.5%	75.6%	93.7%

South Atlantic Region = DC, DE, FL, GA, MD, NC, SC, VA, WV

*The 2019 State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals grade excludes hospitals that have fewer than 50 beds. Report Card grades are as follows: A (80% or more of hospitals with 50+ beds have palliative care), B (60-79%), C (40-59%), D (20-39%), F (less than 20%).

The Coalition to Transform Advanced Care (C-TAC)

The ACT Index, developed by C-TAC, is an evidence-based tool designed to assess the quality of care for individuals with serious illness.¹⁶ It consists of 27 publicly available measures across four domains of influence, providing healthcare leaders, policymakers, regulators, communities, and consumers with valuable insights into the current care experience. By tracking progress at the national and state level and comparing against leaders in different domains, the ACT Index helps identify areas for improvement and informs necessary changes in care. It serves as a catalyst for developing policies and programs that enhance the quality of life for individuals and their families facing serious illness.

According to the 2022 ACT Index Report by C-TAC, Maryland holds the 34th position among all states in the United States on the C-TAC ACT Index ranking. Maryland's ranking of #34 on the C-TAC ACT Index in the 2022 ACT Index Report suggests that there is room for improvement in the state's care experience. The ACT Index offers valuable insights into the current state of care, allowing healthcare leaders, policymakers, regulators, communities, and consumers in Maryland to identify areas that need attention and make informed decisions to enhance the quality of life for individuals and their

¹⁶ Coalition to Transform Advanced Care (2022). Advanced Care Transformation Report 2022. Retrieved June 1, 2023, from: https://thectac.org/wp-content/uploads/2022/10/CTAC-2022_act-index-print-version.pdf

families facing serious illness. By tracking progress at the national and state level and comparing against leaders in different domains, the ACT Index serves as a valuable resource for Maryland to drive positive changes in care delivery and outcomes.

Federal Change Index: State Advanced Care Transformation (ACT) Index by Domain and Change Over Time, 2017 to 2020

State	Domain	2017 Rank	2020 Rank	Change in Rank
Maryland	Caregiving and Community	38	31	7
	Care	48	42	6
	Communication	29	39	-10
	Cost	28	32	-4
	Overall Achievement	43	34	9

The Advanced Care Transformation Report 2020: #34: Maryland

Caregiver & Community Domain	Maryland	United States
Patients who would definitely recommend the home health agency to friends and family	75%	78%
Family willing to recommend this hospice	86%	84%
Seniors with a dedicated healthcare provider (65+)	96.5	93.7
Caregivers (non-professional per Medicare beneficiary)	0.75	0.95
Policies supporting working caregivers (composite indicator, scale 0-9.0)	5.10	3.17
Community support (dollars per adult in poverty 60+)	\$331	\$570
Adults with food insecurity (60+)	11.7%	13.4%
Home-delivered meals (per 100 adults 60+ with independent living difficulty)	3.8	9
Volunteerism among adults (65+)	38.2%	28%
State Rank in Caregiver & Community Domain	#31	---

Care Domain	Maryland	United States
Home healthcare workers (per 1,000 adults aged 75+)	111	174
Hospice emotional and spiritual support	90	90
Hospice help for pain and symptoms	73	75
Hospice training family to care for patient	73	76
Adults getting the help needed when they contacted their home health provider (last 2 months of care)	20.4%	23.8%
Communication Domain	Maryland	United States
Hospital patients discharged without instructions for home recovery	14	14
Deaths at Home	31%	32%
Person- and family-centered care (composite indicator, scale 0-5.0)	1.50	3.04
Medicare fee-for-service beneficiaries with advance care planning	4.89%	4.14%
State Rank in Communication Domain	#39	
Cost Domain	Maryland	United States
30-day hospital readmissions (per 1,000 Medicare beneficiaries 65+)	32.6	39.8
Hospice days per decedent (last six months of life)	24.3	27.3
Hospital days (last two years of life)	16.1	14.2
Intensive care days (last six months of life)	2.2	3.5
Preventable hospitalization (per 1000 Medicare beneficiaries 65+)	46.7	49.4
Home health agency visits (last six months of life)	7.24	8.23
Adults who went without care because of cost in past year (65+)	3.6	4.7
Co-payments (last two years of life)	\$5,134	\$4,453
Total Medicare spending per decedent (last two years of life)	\$92,558	\$78,635
State Rank in Cost Domain	#32	---

NASHP Maryland Initiative

It is important to highlight that Maryland was among the six states chosen in 2023 to take part in the [State Policy Institute to Improve Care for People with Serious Illness](#) (Institute). Led by the National Academy for State Health Policy (NASHP) in collaboration with The John A. Hartford Foundation, the Institute aims to support the selected state teams over a two-year period, providing them with technical assistance from NASHP and subject matter experts in serious illness and palliative care policy. Additionally, CBIZ Optumas and Torrie Fields Analytics will lend their expertise to assist the participating teams in developing state-specific actuarial models for Medicaid palliative care benefits. This comprehensive support and collaboration are expected to facilitate the implementation of effective policies and initiatives that improve the care provided to individuals facing serious illness in Maryland and the other selected states.

Maryland Regulations Related to Hospital Palliative Care¹⁷

In 2015, the Maryland Health Care Commission conducted a study of palliative care programs in hospitals. Data was collected from 11 hospitals in a pilot study. Standards and materials were used from both CAPC as well as the National Quality Forum. Recommendations were made for 37 beds practices, of which 30 were recommended as minimum standards.

Maryland, informed by findings from the legislatively mandated pilot study conducted by the Maryland Health Care Commission on hospital palliative care, updated its hospital licensing regulations to require that hospitals with fifty or more beds establish an active, hospital-wide palliative care program that provides consultation services to patients living with a serious illness.

The Maryland regulations (COMAR 10.07.01.31) on palliative care emphasize the importance of specialized medical care for individuals with serious illnesses or conditions. Palliative care programs are interdisciplinary teams that aim to improve patients' quality of life and provide relief from symptoms, pain, and stress.

COMAR 10.07.01.31 "Palliative care" defined as specialized medical care for individuals with serious illnesses or conditions that:

¹⁷ Maryland Health Care Commission Hospital Palliative Care report see Appendix E.

- (a) Is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness or condition, whatever the diagnosis;*
 - (b) Has the goal of improving quality of life for the patient, the patient's family, and other caregivers;*
 - (c) Is provided at any age and at any stage in a serious illness or condition; and*
 - (d) May be provided along with curative treatment.*
- (27) "Palliative care program" means an interdisciplinary team that provides palliative care service.*

The regulations outline various aspects of palliative care programs, including staffing requirements, palliative care education and training for hospital staff, interdisciplinary plans of care, coordination of services, and continuity of care. The programs are expected to provide counseling on health options, pain management, prognosis, and the availability of psychological, spiritual, and bereavement services. Proper pain and symptom management, along with education and support for caregivers, are also highlighted.

Additionally, the regulations address referrals to hospice services when appropriate, compliance with advance directives and authorized decision makers, access to ethics committees, and participation in quality improvement activities. The Maryland Department of Health, through the Office of Health Care Quality has the authority to access data to ensure compliance with state and federal regulations.

Emerging Recommendation Themes from the Palliative Care Workgroup

While the Palliative Care Services Workgroup is still in the process of finalizing recommendations, several key themes have surfaced during the workgroup discussions. These overarching themes will serve as a foundation for the development of recommendations that will be included in the Final Report to the Legislature.

1. Financing:

- Lack of specific palliative care benefit from Medicare, Medicaid, and insurers
- Limited inclusion in value-based contracts
- Address gaps in services through improved reimbursement

2. Public and Professional Education:

- Increase awareness and understanding
- Differentiate palliative care from hospice

3. Home and Community-based Services:

- Expand palliative care outside of hospitals

- Enhance accessibility and convenience

4. State Advisory Council Partnership:

- Collaborate with the State Advisory Council on Quality Care at End of Life
- Advance care planning and public education initiatives

5. Workforce development:

- Increase the number of trained and credentialed palliative care professionals

6. Funding models:

- Explore funding models used in other states for statewide palliative care services

7. Data collection:

- Implement shorter, more focused surveys for future data collection

8. Stakeholder engagement:

- Engage a wider community-based group for increased stakeholder input

Conclusion

Through collaboration with stakeholders, the Maryland Palliative Care Services Workgroup has identified key themes for recommendations, including financing, education, expanding community-based services, workforce development, funding models, data collection, and stakeholder engagement. The aim is to present actionable strategies that address the identified needs and challenges in the field of palliative care in Maryland.

The Final Report to the Legislature will provide a comprehensive set of specific recommendations based on the workgroup's findings and deliberations. These recommendations will be carefully crafted to enhance the quality and accessibility of palliative care services in the state. It is crucial to recognize the importance of palliative care in enhancing the quality of life for patients with serious illnesses, and integrating it into community-based care.

APPENDICES

APPENDIX A: HB 378

APPENDIX B: Palliative Care Services Workgroup Membership

APPENDIX C: Workgroup Meeting Summaries

APPENDIX D: Statewide Palliative Survey

APPENDIX E: Palliative Care Hospital Report

APPENDIX A

HB 378

Chapter 301

(House Bill 378)

AN ACT concerning

Maryland Health Care Commission – Palliative Care Services – Workgroup

FOR the purpose of requiring the Maryland Health Care Commission to convene a workgroup to study palliative care services and make recommendations to improve palliative care services; and generally relating to the Maryland Health Care Commission and palliative care services.

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND,
That:

(a) (1) The Maryland Health Care Commission shall convene a workgroup of interested stakeholders to study palliative care services and make recommendations to improve palliative care services in the State.

(2) The workgroup convened under paragraph (1) of this subsection shall include representatives of:

- (i) hospice and palliative care providers;
- (ii) health care facilities;
- (iii) patient advocacy groups; and
- (iv) health insurers.

(b) The workgroup shall examine:

- (1) the state of palliative care services offered in the State;
- (2) the capacity of palliative care providers to provide services;
- (3) any geographic areas where significant gaps in palliative care services may exist;
- (4) opportunities to collaborate with key stakeholders who are positioned to develop a strategy or plan for improving and expanding the provision of high-quality palliative medicine and care services;
- (5) the feasibility of financial support for a long-term expansion of palliative care services, including insurance coverage;

(6) a plan for ongoing data collection for purposes of the monitoring and improvement of palliative care services;

(7) engagement strategies for educating the public about palliative care to empower individuals to make informed decisions about an individual's preferred care when faced with serious illness; and

(8) any other strategies that would improve palliative care services.

(c) (1) On or before July 1, 2023, the Maryland Health Care Commission shall submit an interim report of the findings and recommendations of the workgroup, including the need for any legislative initiatives, to the Governor and, in accordance with § 2-1257 of the State Government Article, the General Assembly.

(2) On or before November 1, 2023, the Maryland Health Care Commission shall submit a final report of the findings and recommendations of the workgroup, including the need for any legislative initiatives, to the Governor and, in accordance with § 2-1257 of the State Government Article, the General Assembly.

SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect October 1, 2022. It shall remain effective for a period of 2 years and, at the end of September 30, 2024, this Act, with no further action required by the General Assembly, shall be abrogated and of no further force and effect.

Approved by the Governor, May 12, 2022.

APPENDIX B

Palliative Care Services Workgroup Membership



Palliative Care Work Group Membership

Name	Affiliation	Group Represented
Cathy Hamel CHamel@gilchristcares.org	Gilchrist Hospice	Hospice Provider
Scott Hanel ScHanel@accentcare.com	Seasons Hospice,	Health Facilities Association of Maryland- Nursing home representative
Chris Kearney christopher.d.kearney@gmail.com	Formerly Medstar Union Memorial Palliative Care	State Advisory Council on Quality Care at the End of Life
Marian Grant msggrant@comcast.net	Palliative Care Nurse Practitioner	Nurse provider/CAPC
Erin Davis edavis@mhaonline.org	MD Hospital Association	Maryland Hospital Association
Peggy Funk Peggy.Funk@hnmd.org	Hospice & Palliative Care Network of Maryland	Hospices in Maryland and nationally
Lisa Stone/ Mark Lovelace mlovelace1@stellamaris.org	Stella Maris	Home Health Agency

Cindy Carter cpcarter@aol.com	AARP	AARP-consumer
Cindy Massuda Cindy.Massuda@cms.hhs.gov	CMS	Federal payer
Amanda DiStefano AmandaK.Distefano@maryland.gov	MDoA	Maryland Dept of Aging
Matthew Celentano mcelentano@fblaw.com	Attorney; Commercial Insurers	League of Life Insurers
Cindy Baumhardt-Rivera Cindy.Baumhardt-Rivera@carefirst.com	Carefirst	Blue Cross/Blue Shield of Maryland
Joanna Ruth joannae.ruth@maryland.gov	Maryland Medicaid	Medicaid

APPENDIX C

Workgroup Meeting Summaries



Palliative Care Services Workgroup Meeting
September 21, 2022
Meeting Summary

ATTENDANCE:

Workgroup Members:

Dr. Deneen Bowlin, Carefirst
Cindy Carter, AARP
Matthew Celentano, League of Life
Erin Davis, Maryland Hospital Association
Amanda DiStefano, Maryland Department of Aging
Peggy Funk, Hospice & Palliative Care Network of Maryland
Dr. Marian Grant, Palliative Care Nurse Practitioner and Consultant
Dr. Christopher Kearney, State Advisory Council on Quality Care at End of Life
Cindy Massuda, CMS
Joanna Ruth, Maryland Medicaid

MHCC Staff:

Ben Steffen
Linda Cole
Tracey DeShields
Stacy Howes
Zoram Kaul
Shadae Paul
Catherine Victorine
Cathy Weiss

Interested Parties/Public:

Scott Brown, MyDirectives.com
Allison Ciborowski, Leading Age
Leah Couture, MedStar Union Memorial Hospital
Dr. Ethan Goldstein, MedStar Good Samaritan Hospital
Aaron Greenfield, Greenfield Law, Leading Age
Cathy Grason, Carefirst
Ted Myerson, Nursing home general interest
Sarah Oiveria, Frederick Health
Tracie Shwoyer-Morgan, Gilchrist Hospice

WELCOME AND INTRODUCTIONS:

Ben Steffen, Executive Director of the Maryland Health Care Commission (MHCC) welcomed all participants to the first meeting of the Palliative Care Services Workgroup. After introductions of staff and workgroup members, Mr. Steffen presented some housekeeping items about conduct of zoom meetings (mute microphones; use Q&A feature) and asked participants to hold questions until after the presentations.

REVIEW OF HB 378:

Linda Cole, Chief of Long-Term Care Policy and Planning at MHCC, reviewed the enabling legislation (HB 378). The legislation requires the MHCC to convene a group of interested stakeholders; those representatives have been introduced as workgroup members who explained their connection to the subject of palliative care in Maryland.

Ms. Cole then reviewed the Scope of Work outlined in the bill and explained that the focus of this first meeting would be on the first three bullets: palliative care resources, capacity of providers to offer care, and gaps in resources. Other items included in the Scope of Work, such as collaboration, financial support, public education, and other strategies would be the focus of future meetings.

The timelines include an Interim Report, due July 2023, and a Final Report, due November 2023. Ms. Cole noted that settings recommended to be studied include hospitals, nursing homes, hospices, home health agencies, and community settings.

MHCC WORK AND OTHER STATE STUDIES:

Ms. Cole explained that previous MHCC work included a 2008 “Study of Health Care Services for Children with Life-Threatening Conditions,” conducted jointly with the State Advisory Council on Quality Care at End of Life. In 2015, MHCC conducted a study entitled “Maryland Hospital Palliative Care Programs: Analysis and Recommendations.” While staff recommends collecting data across multiple settings, the focus of the current study is on community-based palliative care.

Ms. Cole noted that the Center to Advance Palliative Care (CAPC), in conducting a nationwide study of palliative care, awarded an “A” to Maryland, primarily in the provision of hospital-based palliative care.

Ms. Cole offered a staff recommendation for a definition of palliative care to guide the work of this group:

“Palliative care is specialized medical care for people living with serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness.

The goal is to improve quality of life for both the patient and family.



Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support.

Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage of a serious illness, and it can be provided along with curative treatment."

Source: Center to Advance Palliative Care

SURVEYS IN OTHER STATES:

Ms. Cole reviewed palliative care work done in four states: Hawaii, Colorado, South Carolina, and Nebraska. Hawaii is cited as a model that inspired work on the development of HB 378. The research reported was limited, as they surveyed 30 programs and received responses from six.

The Colorado research is far more robust and has been repeated three times. It involves a telephone survey of palliative care resources identified in the state. This survey could be a good starting point for Maryland.

South Carolina did not conduct a survey, but relied on the CAPC report for its state. A major focus was on pediatric palliative care.

Nebraska also relied on CAPC data in lieu of a state survey. The report includes case studies to describe the types of patients that might be appropriate for palliative care.

WORKPLAN:

Ms. Cole briefly reviewed the workplan, which had been included in the workgroup mailing. The first three sections describe background and planning work presented at this meeting. Future meetings are planned as follows:

Meeting 2: Review survey instrument and determine how to measure services and gaps.

Meeting 3: Review survey results and recommend complementary data sources.

Meeting 4: Discuss strategy for collaboration and for expansion of financial support.

Meeting 5: Discuss strategy for ongoing data collection and for public education.

Meeting 6: Discuss preliminary findings and draft Interim Report

Meeting 7: Review recommendations

Meeting 8: Develop consensus on final recommendations and review Final Report.

DISCUSSION AND COMMENTS:

Peggy Funk, Executive Director of the Hospice & Palliative Care Network of Maryland, explained the background and development of HB 378 and thanked the MHCC for bringing together this workgroup.



There was some discussion of the CAPC report card. It is self-reported data and focuses primarily on hospital services. Some commenters indicated that patients do not want to stay in hospitals for care, but palliative care services outside the hospital are in limited supply.

Financing of Care:

Mr. Steffen asked the payors how palliative care is financed. Payment is fragmented and provided under various other services. Many employers, as well as the general public, are not aware of palliative care. Representatives of commercial insurers and Carefirst said that they would do some research and supply additional information to the workgroup.

Definition:

Ms. Cole recommended the CAPC definition of palliative care and asked for feedback.

Members stated that this definition is widely used by CAPC and for public education. It has also been endorsed by the National Hospice and Palliative Care Association (NHPCO). Other commenters stated that examples of services are needed. Some commented that it is unclear what the specially trained teams include in an era of workforce shortages.

Ms. Funk clarified the differences between hospice and palliative care. As she stated, all hospice is palliative care, but not all palliative care is hospice. Both involve a multidisciplinary team approach and include spiritual care.

Dr. Grant, Palliative Care Nurse Practitioner and Consultant, indicated that the issue can also be defined in terms of “serious illness” in the general population. She offered to supply staff with data on this.

Settings:

Ms. Cole recommended the following settings for the survey: hospitals, nursing homes, hospices, home health agencies, other community providers. Commenters said that settings are influenced by workforce and payment issues. It was pointed out that settings can also include types of specialty clinics (e.g., oncology, dialysis) that provide palliative care.

State Surveys and Data:

Questions were raised as to why Colorado was recommended, though some members supported this suggestion. It was recommended that staff explore other state programs including the following:

California recently included palliative care in its MediCal (state Medicaid program). Hawaii updated its research within the past year. Massachusetts and Florida are also doing work in this area. Members offered to provide the staff with additional information from other states.



Other:

Mr. Steffen raised questions about Iris Health, Halifax, and other for-profit organizations that might offer palliative care. He also asked how Accountable Care Organizations (ACOs) address this issue.

He also stated that the use of a contractor to help with a statewide survey (or other workgroup tasks) would involve the bid board process, which is limited to contracts up to a maximum of \$50,000.

Next Steps:

Following public comments, Mr. Steffen said that Survey Monkey will be used to set up the next few meetings to address issues as identified in the workplan.





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Palliative Care Services Workgroup Meeting
November 14, 2022
Meeting Summary

ATTENDANCE:

Workgroup Members:

Dr. Deneen Bowlin, CareFirst
Cindy Carter, AARP
Matthew Celentano, League of Life
Erin Davis, Maryland Hospital Association
Amanda DiStefano, Maryland Department of Aging
Peggy Funk, Hospice & Palliative Care Network of Maryland
Dr. Marian Grant, Palliative Care Nurse Practitioner and Consultant
Catherine Hamel, Gilchrist Hospice
Scott Hanel, Accentcare
Dr. Christopher Kearney, State Advisory Council on Quality Care at End of Life
Cindy Massuda, CMS
Joanna Ruth, Medicaid
Kelly Voltran, CMS

MHCC Staff:

Ben Steffen
Linda Cole
Tracey DeShields
Stacy Howes
Zoram Kaul
Catherine Victorine
Cathy Weiss

Interested Parties/Public:

Rachel Adams, MedStar
Scott Brown, My Directives
Allison Ciborowski, Leading Age
Dr. Donald D'Aquila, University of Maryland Clinical Pharmacy Specialist
Dr. Ethan Goldstein, MedStar Good Samaritan Hospital
Ted Myerson, Nursing home general interest
Kathryn Walker, MedStar

WELCOME AND INTRODUCTIONS:

Ben Steffen welcomed all participants to the second meeting of the Palliative Care Services Workgroup. He introduced staff and workgroup members in the conference room and asked participants on zoom to introduce themselves.

Linda Cole asked the workgroup members if there were any comments or corrections on the meeting summary sent for the September 21st meeting. There were no comments.

UPDATES BY PAYERS:

Ms. Cole then stated that she had followed up with payer representatives, asking them to prepare information for this meeting on how palliative care is reimbursed.

Kelly Voltran, representing CMS stated that Medicare has a hospice benefit, but no separate palliative care benefit. Mr. Steffen pointed out that hospice requires a patient to forego curative treatment, while palliative care does not.

Cathy Hamel, Gilchrist Hospice, said that certain palliative care treatments are covered under the hospice per diem. She also said providers (physicians and nurse practitioners) bill Medicare Part B for palliative care consults. She said that advance care planning is covered under Medicare. She added that concurrent care (both hospice and curative care), which was covered by the Centers for Medicare and Medicaid Services Innovation Center (CMMI) under grants was successful, but not continued. Dr. Marian Grant said that the CMMI model of concurrent care was established, but the entrance requirements for patients were so stringent that there were insufficient patients, and therefore it was discontinued.

Joanna Ruth, representing Maryland Medicaid, said that Medicaid funding is similar to Medicare. Some covered services may be considered palliative care, but there is no specific benefit. Cathy Hamel stated that Medicaid will cover concurrent care for pediatric patients. Ms. Ruth said that she will follow up to see if Medicaid has any plans to cover palliative care in the future.

Dr. Deneen Bowlin, representing CareFirst said that there is no separate benefit for palliative care. Hospice and palliative care are covered under employer contracts. Medicare Advantage covers some palliative care services under contract with Aspire. Dr. Chris Kearney asked if CareFirst had previously had a commercial benefit for palliative care. He believed it was concurrent care for younger populations when Tim Cox was working at CareFirst.

Dr. Grant clarified that hospice is palliative care at the end of life, but earlier palliative care is not hospice. We need to come up with creative solutions to financing issues.

Mr. Steffen said that the MHCC has found that advance care planning is not used much by primary care physicians. He noted that palliative care seems to be a contract-by-contract option and asked if it was a pricey option.

Matt Celentano, representing League of Life, said that insurance carriers whom he contacted struggled to reply. Most have some hospice/palliative care benefit, but it is usually treated as the same thing. He offered that if the group can come up with some CPT codes, he could check to see which services are covered.

Dr. D'Aquila said that the Veterans Administration (VA) is very well versed in providing concurrent care. He asked if that may be a model to consider. Dr. Grant said that the VA has a comprehensive

program, but it is an integrated system, unlike the rest of the healthcare system, so results cannot be generalized.

Dr. D'Aquila said that Medicare Advantage has low use in Maryland. He asked if the Health Services Cost Review Commission (HSCRC) covers services under "serious illness programs." Mr. Steffen said that the HSCRC application to CMMI to allow HSCRC to establish lower hospital rates for Maryland Medicare Advantage plans had been rejected. Maryland is currently considering one-time funding support to Medicare Advantage plans, while a long-term plan is developed.

Mr. Steffen said that HSCRC is planning for the next stage of the Total Cost of Care (TCOC) expansion. Workgroups will be formed to identify opportunities for greater alignment with the TCOC model among various health care providers that are not directly linked to TCOC. One workgroup will focus on post-acute care payment and quality initiatives.

Ms. Cole summarized this discussion of payment for palliative care that the current situation seems to indicate very few, if any, specific palliative care benefits. This information, along with the survey, will help to describe the current situation. Future discussions will help the workgroup to develop recommendations about expansion of palliative care benefits.

REVIEW OF DRAFT SURVEY:

Ms. Cole continued with the review of the draft palliative care survey. She pointed out that this draft survey had been mailed in advance for review by workgroup members. She received detailed comments from Dr. Grant but expected full participation by workgroup members.

Dr. Kearney asked what definition of palliative care was to be used for the survey. Ms. Cole referred him to the discussion at the first meeting of the workgroup and the selection of the definition developed by the Center to Advance Palliative Care (CAPC) as follows:

Palliative care is specialized medical care for people living with serious illness.

This type of care is focused on providing relief from the symptoms and stress of the illness.

The goal is to improve quality of life for both the patient and family.

Palliative care is provided by a specially-trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support.

Palliative care is based on the needs of the patient, not on the patient's prognosis.

It is appropriate at any age and at any stage of a serious illness, and it can be provided along with curative treatment.

The survey, which will be sent by email to identified staff at the provider programs and facilities will be followed up by telephone surveys so that the interviewer can probe for detailed responses.

Representatives (such as MHA, HFAM, Hospice & Palliative Care Network) will be asked to advise on the best person/department to contact for the survey.

Ms. Cole said that we are interested only in formal programs that meet the palliative care definition above. For those programs that offer palliative care under contract (e.g., nursing homes that contract with hospices), we will identify the program and with whom they contract. That would identify the site of care without duplicating the count of providers.

There were recommendations to modify question 5 to address hospital programs and contracts. There were wording suggestions for question 7(f) to modify community setting options. Some suggestions

were made to include a general statement of possible losses on question 8. For question 9, recommendations included adding measures such as reduction in hospital readmissions and use of emergency departments.

Dr. Kearney asked a general question about the length of the survey and level of detail. Ms. Cole responded that the legislative directive is quite broad. She also stated that the basic survey (modified by staff and the workgroup) has been used in other states, including three times in Colorado and twice in Maine. Dr. Kearney asked if additional data is available from CAPC or the Palliative Care Collaborative. Ms. Cole summarized some of the limitations of the data collected by CAPC, including a greater focus on hospital and not community-based palliative care.

Ms. Cole reviewed the sites recommended for the survey: licensed general hospitals; licensed nursing homes; licensed hospices; licensed home health agencies; other identified community providers as identified in the survey. There were no additional comments on this.

The modified survey will be included in the mailing to the workgroup.

OTHER ISSUES:

Scott Brown asked if Maryland Order for Life-Sustaining Treatment (MOLST) forms were identified could that be used to document registries. Mr. Steffen replied that this is addressed by other MHCC initiatives on advance directives.

Cindy Carter asked if there will be a survey of caregivers in the community. Peggy Funk added that it would be good to get the perspective of caregivers. Ms. Cole responded that this survey is directed to licensed facilities in Maryland, but another approach could be considered for caregivers.

There was mention of the importance of telehealth. Ms. Cole pointed out that this is included in the survey.

NEXT STEPS:

Mr. Steffen thanked everyone for their participation. Ms. Cole said that the next workgroup meeting is scheduled for January 9, 2023. Ms. Cole said that she will keep the group updated on the process of getting out the bid board for the survey. The agenda for that meeting will also address “improving and expanding palliative care” as well as further discussion on financing, including what exists now and what is needed in the future.



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TELEPHONE: 410-764-3460 FAX: 410-358-1236

Palliative Care Services Workgroup Meeting
January 9, 2023
Meeting Summary

ATTENDANCE:

Workgroup Members:

Dr. Deneen Bowlin, CareFirst
Cindy Carter, AARP
Erin Davis, Maryland Hospital Association (MHA)
Dr. Marian Grant, Palliative Care Nurse Practitioner and Consultant
Amanda DiStefano, Maryland Department of Aging
Peggy Funk, Hospice & Palliative Care Network of Maryland
Dr. Christopher Kearney, State Advisory Council on End of Life Care
Cindy Massuda, CMS
Joanna Ruth, Maryland Medicaid

MHCC Staff:

Ben Steffen
Linda Cole
Tracey DeShields
Dr. Stacy Howes
Zoram Kaul
Cathy Weiss

Interested Parties/Public:

Dr. Rachel Adams, MedStar Health
Tara Coles
Leah Couture, MedStar Health
Tiffany Daniel, AARP
Dr. Ethan Goldstein, MedStar Health
Ted Meyerson, Nursing home/ General Interest
Maria Moen
Dr. Dan Morhaim, Retired Physician and State Delegate
Rebecca Swain-Eng, SEA Healthcare
Mary Alfonso-Torres, Seasons Hospice
Kelly Voltran, CMS

WELCOME AND UPDATES:

Linda Cole welcomed the participants to the third meeting of the Palliative Care Services Workgroup. She asked if there were any comments or corrections to the November 14th meeting summary. She noted that this is posted on our website in case anyone has comments.

Ms. Cole reported that the bid board contract for conducting the statewide palliative care survey was posted and responses were received on December 23rd. After reviewing the proposals, staff awarded the contract to SEA Healthcare. Rebecca Swain-Eng, CEO of SEA Healthcare was introduced to the workgroup. Results from this survey will be shared with the workgroup at future meetings.

CONSUMER PERSPECTIVES ON PALLIATIVE CARE:

Ms. Cole said that Cindy Carter, representing AARP, had stated in previous meetings that our survey of healthcare facilities does not take into account the perspective of patients and their caregivers. Ms. Cole introduced Cindy Carter and Tiffany Daniel to share their perspectives.

Ms. Carter explained that her assignment for this presentation was to address four questions:

1. How were you referred to palliative care/
2. What worked well for you?
3. What obstacles did you encounter?
4. What recommendations can you make to the workgroup?

Ms. Carter stated that she has run the Cancer Support Foundation for 18 years, is a four-time caregiver, and is a cancer survivor. Her experience is that patients are offered hospice or no care; palliative care is not mentioned. In her experience, most patients are treated in the hospital, but they have little or no follow up when they go home. Patients who do not have an able-bodied caregiver at home do not get needed services. What is needed is help with taking care of patients' needs at home.

Dr. Marian Grant noted that she agreed with what Ms. Carter reported. However, she noted that the gaps in services are not just for cancer care, but for all serious illnesses. She also noted that the need for supportive services in the home (e.g., help with activities of daily living) is not palliative care, which is medical care. The lack of funding and access to non-medical support services in the community is a general failure of the health care system, but not the focus of this workgroup.

Dr. Chris Kearney said that palliative care has a role in the hospital, especially when a patient is admitted for uncontrolled symptoms. He agreed that more needs to be done on social determinants of health.

Tiffany Daniel explained her family's experience as both of her grandmothers became caregivers for her grandfathers. Her niece also experienced a cancer diagnosis. Her experience was with the Veterans Administration. Her family was not referred to palliative care. They delayed use of hospice care in the home. Family members rotated providing needed care at home. She said that family members need training to provide such care.

Dr. Dan Morhaim asked about Ms. Daniel's reference to "hospice care in the last days." He stated that hospice should be provided for months.

DISCUSSION OF STRATEGIES FOR COLLABORATION FOR IMPROVING AND EXPANDING PALLIATIVE CARE SERVICES:

Ben Steffen noted that there seems to be no agreement on where palliative care fits. Is it end of life care or curative care? This is important for payers.

Dr. Grant agreed and pointed out that in areas such as cardiology there is not the same confusion as with cancer care. Palliative care can be offered early in any serious illness until the end of the illness. At the end, care can shift to hospice.

Peggy Funk agreed with Dr. Grant and said that hospice is a Medicare benefit that is offered when a physician indicates that, if the illness follows the average trajectory, the patient has six months or less to live. Many patients do not die within six months, and the benefit can be extended. Palliative care is offered earlier to help manage symptoms and improve the quality of life. Hospice care is part of palliative care; however, hospice care is not curative.

Dr. Rachel Adams said that there is lack of education about palliative care. Also, there need to be incentives to refer to palliative care. Guidelines recommend that for cancer patients they should be referred to palliative care within eight weeks; however, these are only guidelines. She noted that MedStar has nine palliative care programs.

Dr. Grant mentioned that the Hartford Foundation is working on messaging for providers and patients on palliative care. The research indicates that messages should not differentiate palliative care from hospice. References to hospice often scare patients away from using palliative care services.

Dr. Grant also mentioned Clinical Guidelines on referral to palliative care. She stated that some hospitals have triggers in their electronic health records, but these have mixed results. Most hospitals have inpatient palliative care only. At the University of Maryland, there are inpatient palliative care programs, but nothing post discharge.

Dr. Adams said that MedStar has a very successful palliative care program embedded in its inpatient program. MedStar also has community-based programs. Through the PATCH program, telehealth based palliative care is offered. She noted that there are also fellowship programs for palliative care at both MedStar and the University of Maryland.

Erin Davis stated that palliative care is needed across all service lines in hospitals and across all settings. Many providers are not comfortable with speaking about palliative care and patients are often lost in transitions of care.

Ms. Funk pointed out that hospitals do a good job of providing palliative care because recent legislation required all Maryland hospitals with 50 beds or more to provide a palliative care program. The need, and the focus of this workgroup, is on palliative care within the community.

DISCUSSION OF STRATEGIES FOR EXPANDING FINANCIAL SUPPORT FOR PALLIATIVE CARE:

Ms. Funk mentioned that Hospice of Washington County has a freestanding palliative care community program. However, this service is expensive and is provided at a financial loss.

Dr. Grant said that other states, such as California and Hawaii, have made palliative care a required benefit under their state Medicaid program. Such an effort encourages the development of palliative care programs across the state. She asked what can be done under the Health Care Services Cost Review Commission (HSCRC) Total Cost of Care waiver.

Dr. Kearney pointed out that advocates need to convince hospital administrators that palliative care is effective in reducing average length of stay, hospital readmissions, use of ICU days. Hospitals are losing money in funding these programs. They would like to share costs under the Total Cost of Care.

Dr. Adams said that MedStar is supporting the palliative care programs. However, many hospital systems are losing staff and cutting costs.

Ms. Davis said that there are opportunities to work under the Total Cost of Care model. She would like to see the data produced by the survey to be able to make the case for the program. The Total Cost of Care program has a goal to fund innovative programs.

Dr. Morhaim asked how you would quantify savings under the Total Cost of Care. Dr. Grant said that data has been provided to individual institutions to justify the programs.

Dr. Grant said that Medicare pays for medical services, symptom management, advance care planning. It does not pay for time spent discussing issues with the family or for social workers or chaplains. She indicated that one method of payment was bundled payment (set amount per month per patient) for all services needed for a

seriously ill patient. Medicare Advantage plans offer some supplementary benefits, but these are narrowly defined to limit costs.

Ms. Davis said that HSCRC does pay for Episodes of Care, but how would they be defined? Dr. Grant said that California and Hawaii have defined this, but it needs to be done on a state-specific basis.

Mr. Steffen said that he did not know how many Episodes of Care are defined. It would need to be condition-specific. He also questioned how effective this would be in the absence of mandates.

Dr. Kearney said that there was a program that CareFirst funded and that would help to identify the most expensive patients. Dr. Bowlin said that this was an earlier program at CareFirst, but that it had been discontinued. Dr. Adams said that it is still being funded at MedStar. Dr. Bowlin said that she would look into it and do further research.

Dr. Grant also mentioned that the National Academy for State Health Policy (NASHP) is offering to help states develop palliative care programs by offering technical support to a few selected states who apply and are accepted. This does require buy in from several state agencies. She said that she would share this with MHCC staff.

Dr. Morhaim indicated that there needs to be demand from patients. He hoped that recent legislation on Advance Directives would help to identify and define palliative care. He would expect that an item to be checked would be to request a palliative care consult. Dr. Kearney stated that he has tried to sign up and that the process is challenging. Scott Brown of My Directives said that he appreciated the feedback.

NEXT STEPS:

Ms. Davis asked MHCC staff to alert them when the survey was about to start, so that they can encourage participation among their members.

Ms. Cole said that the next step is implementation of the palliative care survey. The group will reconvene when there is data to share.

She thanked the group for a lively discussion and for their participation. She encouraged members to reach out by email if there are questions prior to the next meeting.



Palliative Care Services Workgroup Meeting

May 23, 2023

Meeting Summary

ATTENDANCE:

Workgroup Members:

Dr. Deneen Bowlin, Carefirst
Cindy Carter, AARP
Matthew Celentano, League of Life
Erin Davis, Maryland Hospital Association
Dr. Marian Grant, Palliative Care Nurse Practitioner and Consultant
Cathy Hamel, Gilchrist Hospice
Amanda DeStefano, Maryland Department of Aging
Heather Guerieri, Compass Hospice (for Peggy Funk)
Dr. Christopher Kearney, State Advisory Council on Quality Care at End of Life
Kelly Voltran, CMS

MHCC Staff:

Ben Steffen
Linda Cole
Tracey DeShields
Dr. Stacy Howes
Catherine Victorine
Cathy Weiss

Interested Parties/Public:

Regina Bodnar
Whit Dunkle
Monica Escalante
Benjamin Goldstein
Sarah Hemming
Louise Knight
Dr. Dan Morhaim
Ted Myerson
Shirley Otis-Greene
Rebecca Swain-Eng
Lisa Tompkins-Brown

WELCOME AND UPDATES:

Ben Steffen welcomed everyone to the fourth meeting of this workgroup. Linda Cole noted that although the workgroup has not met since January, staff have been moving ahead with the palliative care work.

Ms. Cole noted that SEA Healthcare, a health services research and quality improvement consulting firm was awarded the contract to conduct the statewide palliative care survey. They subcontracted with Tenacity Solutions for assistance with quantitative and qualitative data analysis. She noted that the preliminary survey results will be the focus of today's discussion.

In March, we were notified that Maryland was one of six states selected to participate in the State Policy Institute to Improve Care for People with Serious Illness. This group is directed by the National Academy for State Health Policy (NASHP). States will receive technical assistance, sharing palliative care developments, as well as receiving actuarial support to develop models for financing.

In addition, at the request of Leading Age, an organization representing a diverse range of long-term care providers, MHCC staff and workgroup members Peggy Funk and Dr. Marian Grant described the work of this group as well as the development of palliative care in Maryland.

SEA PRESENTATION: PRELIMINARY DATA FROM STATEWIDE SURVEY:

Rebecca Swain-Eng began by describing the process for data collection. The initial survey had to be retooled from a telephone survey to a web-based survey. Beta testing was conducted using volunteers from various healthcare settings.

Since the workgroup had agreed that the survey would be used in four settings, the survey was sent to:

- Hospitals (46)
- Nursing homes (227)
- Hospices (27)
- Home Health Agencies (56)

Reaching the appropriate individuals in each organization was a very complex task, and data collection included multiple follow-up emails and phone calls. The data collection, originally planned for February 22-March 24th, was extended to April 30th to increase response rates.

Ms. Swain-Eng then did a SWOT analysis to review the Strengths, Weaknesses, Opportunities, and Threats gleaned from this process. She also explained that a product of this data collection would be the development of a Palliative Care Provider Directory that would include not only providers who responded to the survey, but also organizations that the research team can confirm have a program by publicly available data. Workgroup members agreed that this would be a useful resource.

Ms. Swain Eng reported an overall response rate of 51%. However, when programs were eliminated if they did not meet the Center to Advance Palliative Care (CAPC) definition, or if they did not complete the entire survey, the responses used in data analysis were 36%. This ranged from 89% for hospices to 45% for nursing homes.

The data presented included: organizational types by region; management of palliative care services; years of providing palliative care services; multi-disciplinary teams composition; program staff roles; certified staff; payers; and billing. For more details, see slides entitled: "Palliative Care Workgroup Meeting MHCC Palliative Care Survey".

Finally, Ms. Swain-Eng provided recommendations for future data collection, including making the survey more focused and briefer; expanding stakeholder engagement to include family providers; evaluate payer types to understand reimbursement policies.

DISCUSSION:

There were some questions from the group to understand the response rates and how the numbers went from 359 surveyed, to 182 respondents to 65 useable surveys. This is further addressed in the slides.

Questions were raised about how staffing questions were formulated. Some were multiple choice (drop down menu) and some were open-ended.

Ben Steffen asked about how value-based care was defined. Lisa Tompkins-Brown responded that there were two questions. One asked if any services were offered under a value-based contracts (yes/no); the other asked the percentage of revenue generated from value-based care. Dr. Grant responded that some hospices have value-based contracts for community care with commercial payers.

Ms. Swain-Eng stated that many programs used contractors to provide palliative care services. For example, Gilchrist provides palliative care for hospitals and nursing homes. Dr. Grant said that palliative care is a unique skill set.

It was noted that most palliative care programs are in urban areas. Other states have used Medicaid benefits to reimburse such care statewide. Heather Guerieri noted that if you pay for palliative care, it will be developed.

Cindy Carter noted that, even in urban areas, there is little to no palliative care provided in the home. If there is reimbursement, this is a way to keep people out of the hospital.

Mr. Steffen asked the payers to discuss their benefits for palliative care. Kelly Voltran, CMS said that the only dedicated benefit is the Medicare hospice benefit. The CMS Innovation Center has funded some models of concurrent care, that is both curative and supportive treatment. It was also mentioned by the workgroup that concurrent care is funded for pediatrics and for Veterans.

Dr. Bowlin, Carefirst said that Carefirst has a pilot with some members in hospitals. . Dr. Chris Kearney said that the previous Carefirst program was a bundled payment program for hospitals and also included care in the community. The current pilot focuses on initiation of palliative care to patients in participating hospitals with continuation of the palliative care into the community.

Matt Celentano said that for commercial insurers it depends on the benefit. He did not have specific data. There is not much value-based care in Maryland; it exists mostly for primary care.

INTERIM REPORT AND RECOMMENDATIONS:

Ms. Cole then reviewed the topics outlined in the legislation that need to be addressed in the Interim Report. She opened discussion on what can be done to address gaps in services, encourage collaboration, address financing, and the other issues outlined.

Dr. Kearney said that the State Advisory Council on Quality Care at End of Life could assist with Advance Care Planning and public education. Dr. Grant cited her work with CTAC (??) which is collaborating with the American Heart Association on palliative care for cardiac patients.

The National Academy for State Health Policy (NASHP) can assist with financial and actuarial analysis. It was mentioned that there are several states that have made progress on Medicaid funding for palliative care, including New Jersey, California, Illinois, Hawaii.

Erin Davis also mentioned work in Arizona to develop community-based palliative care.

Rebecca Swain-Eng mentioned some financial recommendations, including working with policymakers and insurance companies, engaging at the federal level to raise awareness of

palliative care services, identify regulatory barriers, conduct cost-effectiveness studies and other pilot studies.

In terms of gaps in services, Dr. Grant and Ms. Guerieri stated that once funding is established, services will be developed. Dr. Grant cited California where Medicaid coverage is mandated and palliative care services exist in every county. Cathy Weiss asked what licensure system or quality control exists to assure that services provided meet standards. Dr. Grant said she would supply that information.

It was mentioned that there is currently no funding for messaging.

NEXT STEPS:

Ms. Cole mentioned that the group has a short timeframe. She will incorporate comments from today's meeting to develop some themes for draft recommendations. A status report will be presented to the Commission at its June meeting. The workgroup will reconvene on June 28th to review the draft Interim Report. She noted that we have time to refine recommendations prior to the final report, which is due November 1st.



MARYLAND
Health Care
Commission

Randolph S. Sergent, Esq., Chairman
Ben Steffen, Executive Director

Palliative Care Services Workgroup Meeting

June 28, 2023

Meeting Summary

**PLEASE NOTE THAT THE MEETING SUMMARY FOR THIS MEETING IS
CURRENTLY BEING PROCESSED**

APPENDIX D

Statewide Palliative Care Survey



Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Introduction and Survey Eligibility

The Maryland Health Care Commission (MHCC) is conducting a “Prevalence of Palliative Care in Maryland Survey” (“Survey”) for hospitals, home health organizations, hospices, and nursing homes in partnership with SEA Healthcare, a health services research firm.

Formal palliative care programs in Maryland are asked to complete this Survey on behalf of their organization. We are also tracking the number of organizations that do not currently have a formal Palliative Care Program as well, so we ask that everyone who received an invite complete the Survey through Question 3, and if your organization is eligible, please complete the full Survey.

This Survey was authorized by House Bill 378. Oversight is provided by the Maryland Health Care Commission with contractor support from SEA Healthcare. The purpose of the Survey is to study palliative care services and to make recommendations to improve palliative services in Maryland to the Maryland Health Care Commission.

We estimate it will take you no more than 45 minutes to complete this Survey. As long as you use the same IP address, your survey responses are saved and you may come back at a later time to finish the Survey if cannot complete the survey in one sitting.

Please complete the Survey by March 24, 2023, or earlier. If there is a different person at your organization that should be contacted to complete this survey, please forward them the Survey link.

Questions? Please reach out to the MHCC/SEA Healthcare Project lead contractor, Rebecca Swain-Eng, DHSc, MS, CAE at rswaineng@swainengassociates.com.

**We thank you in advance for your participation in this Survey.
[PDF Link to all Survey Questions](#) if you wish to review and come back.**

* 1. Please provide your name, name of your organization, position, email and phone number.

Full Name and
Credentials

Organization

Email

Phone Number

* 2. Are you authorized to answer detailed questions about your organization's palliative care program and services offered?

Yes

No

* 3. This Survey is focused on organizations that have a formal palliative care program. For the purposes of this survey, we are utilizing the Center to Advance Palliative Care's (CAPC) definition of a formal palliative care program.

“Palliative care is specialized medical care for people living with serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and family. Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at any stage of a serious illness, and it can be provided along with curative treatment.”-CAPC

Does your organization have a Formal Palliative Care Program as defined by the CAPC definition that either directly or by contractual arrangement provides palliative care services to your patients/clients/residents?

Yes

No



Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Palliative Care Program Details

* 4. Please provide details about the Director of your palliative care program.

Palliative Care

Program Director

Name and Credentials

Role (Clinical,

Administrative or

Both)

Administrator

Specialty/ Clinical

Background (if

applicable)

Palliative Care

Program Director

Phone Number

Palliative Care

Program Director

Email

* 5. Is your palliative care program provided under contract by another clinical partner such as a vendor, local referral program or other?

No

Yes (please list the names of clinical partner(s) who provide palliative care services for your patients in your organization)

* 6. How many years has your organization been providing palliative care services?

- Less than 1 year
- Between 1-2 years
- Between 2-5 years
- Between 5-10 years
- 10 years or longer

* 7. What type of organization do you represent?

- Hospital
- Hospice Program
- Nursing Home or Skilled Rehabilitation Facility
- Home Health Program
- Other (please specify)

* 8. Do you oversee and run your palliative care program with internal program staff or do you contract out the management of your palliative care program to another organization?

- Independently run our palliative care program without any outside support
- Contract out with another organization to provide palliative care services (please provide the name of the organization you contract with to provide palliative services)

- None of the above



Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Palliative Care Program Organization and Staffing

* 9. **Hospitals Only Question**

If you are not a **hospital** write "Not Applicable" in the comment box.

Please describe where your palliative care program fits into the overall structure of your organization. What area or department of your organization provides oversight and leadership for your palliative care program?

* 10. Who is part of your multi-disciplinary team that supports your palliative program?

Check all that apply.

- Physician (MD/DO)
- Physician Assistant
- Advanced Practice Nurse/Nurse Practitioner
- Registered Nurse
- Licensed Practical Nurse
- Pain Management Specialist
- Patients' Primary Care Providers
- Social Worker
- Chaplain
- Pharmacist
- Pscyhologist/Counselor
- Physical Therapist or Occupational Therapist
- Speech Language Therapist
- Dietician
- Psychiatrist
- Nursing Assistant or Aide
- Office Manager/Administrative Assistant
- Hospice Liaison
- Volunteers
- Other (please specify)

11. In **2022**, please indicate how many full-time staff your palliative care program had in each discipline? Please enter a numerical answer to the closest number of whole FTEs (0, 1, 2, 3, etc.)

Physician

Physician Assistant

Advanced Practice
Nurse/Nurse
Practitioner

Registered Nurse

Licensed Practical
Nurse

Pain Management
Specialist

Social Worker

Chaplain

Pharmacist

Psychologist/Counselo
r

Physical Therapist

Occupational
Therapist

Speech Language
Therapist

Dietician

Psychiatrist

Nursing Assistant or
Aide

Office
Manager/Administrativ
e Assistant

Hospice Liaison

Unknown (We contract
out our palliative care
services through an
outside organization.)

* 12. In **2022**, please indicate how many part-time staff your palliative care program had in each discipline? Please indicate the number of PT to the 0.25 PT equivalent in each box (e.g., 0,1. 1.5, 2.25, etc.)

Physician

Physician Assistant

Advanced Practice Nurse/Nurse Practitioner

Registered Nurse

Licensed Practical Nurse

Pain Management Specialist

Social Worker

Chaplain

Pharmacist

Psychologist/Counselor

Physical Therapist

Occupational Therapist

Speech Language Therapist

Dietician

Psychiatrist

Nursing Assistant or Aide

Office Manager/Administrative Assistant

Hospice Liaison

Unknown (We contract out our palliative care services through an outside organization.)

* 13. How many of your staff members in your palliative care program are fellowship trained, board certified, or specialty certified in hospice and palliative care? Please indicate the total number of staff certified by discipline below.

Physician (MD/DO)	<input type="text"/>
Advanced Practice Registered Nurse	<input type="text"/>
Advanced Practice Provider-PA/NP	<input type="text"/>
Nurse-RN/LPN	<input type="text"/>
Social Worker	<input type="text"/>
Psychologist	<input type="text"/>
Pediatric Nurse	<input type="text"/>
Certified Nursing Assistant	<input type="text"/>
Physical Therapist	<input type="text"/>
Occupational Therapist	<input type="text"/>
Speech Language Therapist	<input type="text"/>
Pharmacist	<input type="text"/>
Other	<input type="text"/>
Unknown	<input type="text"/>

* 14. Please indicate the percentage of palliative care services by care settings that your palliative care program provided in 2022. Indicate the approximate percentage of total services provided by care setting. (e.g., Hospital Inpatient 80 , Hospital outpatient 20). Your total percentage must add up to 100.

Hospital - Inpatient	<input type="text"/>
Hospital - Outpatient	<input type="text"/>
Outpatient Clinic - Primary Care	<input type="text"/>
Outpatient Clinic - Specialty Clinic	<input type="text"/>
Nursing Home	<input type="text"/>
Hospice Center	<input type="text"/>
Patient Home	<input type="text"/>
Telehealth	<input type="text"/>
Other	<input type="text"/>

* 15. Do you have any preferred hospice partners for continuity of care referrals?

No

Yes (please specify your preferred hospice partners)

Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Consultation Services, Referrals and Discharges

* 16. Does your palliative care program have or offer dedicated palliative care **Consultation Services**?

Yes

No

* 17. Do you utilize telehealth services as part of your palliative care consultation service provisions?

Yes

No

*** 18. Hospital Palliative Care Programs Only**

If you are not a **hospital**, choose "Not Applicable".

Which department, specialty, discipline, organization or group do most of your palliative care patient referrals for palliative care services come from? Please choose one answer.

- Oncology
- Intensive Care
- Emergency Department
- Hospitalists
- Pediatrics
- Neurology
- Patient Advocacy Organization
- Patients or Family Members
- Not Applicable
- Other (please specify)

*** 19. Community-Based Palliative Care Programs Only**

If you are not a **community-based program**, please choose "Not Applicable".

Which department, specialty, discipline, organization or group do most of your palliative care patient referrals for palliative care services come from? Please choose one answer.

- Hospitals
- Hospices
- Home Health Programs
- Nursing Homes
- Oncology Department
- Intensive Care
- Emergency Department
- Pediatrics - Inpatient
- Neurology - Inpatient
- Neurology - Outpatient
- Patients or Family Members
- Patient Advocacy Organizations
- Not Applicable
- Other (please specify)

* 20. What percentage of patients receiving palliative care services in **2022** were discharged to the following locations? Your total percentage must add up to 100.

Home (no outside care)

Hospital

Home with Home Health Services

Home with Hospice Services

Medicare Certified Home Health Agency

Nursing Home

Hospice Center

Deceased



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Palliative Care Program Accreditation

* 21. Is your palliative care program currently accredited or certified and, if so, by which organization(s) or program(s)? Please check all that apply.

- The Joint Commission Palliative Care Certification
- Community Health Accreditation Partner (CHAP) Palliative Care Certification
- Accreditation Commission for Health Care, Inc. (ACHC) Palliative Care Distinction
- Maryland Office of Health Care Quality (OHCQ)
- Other (please specify)

* 22. If you answered no to **Question 22**, do you plan to or are you considering seeking certification or accreditation for your palliative care program?

- Yes, we plan to seek palliative care certification or accreditation in the next year
- Yes, we are considering seeking palliative care certification or accreditation in the future
- No, we have no plans to seek palliative care certification or accreditation at this time.
- Not applicable (indicated our organization already has certification or accreditation in Question 22)
- Other (please specify)



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Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Service Areas

* 23. Which jurisdictions in Maryland does your palliative care program serve? Select all that apply.

- Allegany County
- Anne Arundel County
- Baltimore City
- Baltimore County
- Calvert County
- Caroline County
- Carroll County
- Cecil County
- Charles County
- Dorchester County
- Frederick County
- Garrett County
- Harford County
- Howard County
- Kent County
- Montgomery County
- Prince George's County
- Queen Anne's County
- Somerset County
- St. Mary's County
- Talbot County
- Washington County
- Wicomico County
- Worcester County



Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Palliative Care Patient Services

* 24. When are your palliative care program services and consults available for your patients/residents?

- 24 hours/7 days a week
- 24 hours/5 days a week Monday-Friday
- Business Hours/Monday-Friday
- Other (please specify)

* 25. How many patients received palliative care services through your palliative care program in **2021 and 2022?**

2021

2022

* 26. How many palliative care consults were provided by your palliative care program in **2021 and 2022?**

2021

2022

* 27. How many patients were referred to an outside organization for a palliative care consult in **2021 and 2022?**

2021

2022

* 28. Did your organization provide less, more or the same amount of palliative care services, consults and referrals for consults in **2019** (pre-pandemic) than in 2022 on average?

- Less services, consults and referrals in 2022 than in 2019
- Same amount of services, consults and referrals in 2022 and 2019
- More services, consults and referrals in 2022 than in 2019
- Not applicable. Our palliative care program was not in operation in 2019.
- Other (please specify)

* 29. Please check the boxes for the five (5) most frequent palliative care services provided to your patients/residents in **2022**.

- Pain and Symptom Management
- Advance Care Planning Discussions
- Patient and Family Meetings to Support Goals of Palliative Care
- Social Support
- Emotional or Spiritual Support for Patient and Family
- Family or Caregiver Support
- General Support and Advice
- Care Techniques to Improve Patient Comfort and Sense of Wellbeing
- Communication and Care Coordination
- Referrals
- Other (please specify)

* 30. On average, how long do you provide palliative care service to patients/residents- number of visits and/or average length of stay in days? **Please select either option or both if you track both items. (Respond with whole numbers).**

Average Number of
Visits per
patient/resident

Average length of stay
in Days per
patient/resident

* 31. Did your palliative care program utilize telehealth to provide any palliative care services in **2022**?

- Yes
- No

* 32. What services do you provide to family and caregivers of your patients that receive palliative care? Enter "None" if you do not provide any services to families or caregivers.

* 33. Do you offer bereavement services to family or caregivers? (Bereavement services may include emotional, psychosocial, and spiritual support provided to individuals and families to assist with grief, loss, and adjustment after the death of a loved one.)

Yes

No

34. What percentage of the time do you provide palliative care services to the following groups on average? Please enter whole numbers (average) and the total percentage must add up to 100.

Patients Alone

Patients with their
Family/Caregiver

Family/Caregiver(s)
Alone

Prevalence of Palliative Care in Maryland

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Advanced Care Planning (ACP)

* 35. What Advanced Care Planning (ACP) forms do you offer to your patients? Select all that apply.

- Maryland Power of Attorney (MDPOA)
- Maryland Advanced Directive Document (Planning for Future Health Care Decisions)
- Maryland Advanced Directive translated (Spanish)
- Living Will
- Maryland Order for Life Sustaining Treatment (MOLST)
- After My Death Form
- National Hospice and Palliative Care Organization CaringInfo Advance Directors
- None
- Other (please specify)

* 36. What ACP form does your palliative care program use most frequently? Please select one answer.

- Maryland Power of Attorney (MDPOA)
- Maryland Advanced Directive Document (Planning for Future Health Care Decisions)
- Maryland Advanced Directive translated
- Living Will
- Maryland Order for Life Sustaining Treatment (MOLST)
- After My Death Form
- National Hospice and Palliative Care Organization CaringInfo Advance Directors
- Other (please specify)

* 37. When patients enter your palliative care program, on average which ACP form(s) do they already have completed? Check all that apply.

- Maryland Power of Attorney (MDPOA)
- Maryland Advanced Directive Document (Planning for Future Health Care Decisions)
- Maryland Advanced Directive translated
- Living Will
- Maryland Order for Life Sustaining Treatment (MOLST)
- After My Death Form
- National Hospice and Palliative Care Organization CaringInfo Advance Directors
- None
- Other (please specify)

* 38. In **2022**, what percentage of your patients completed the MOLST?

- 0 % (it is not used in our palliative care program)
- 1-20% of the time in 2022
- 21-40% of the time in 2022
- 41-60% of the time in 2022
- 61-80% of the time in 2022
- 81-100% of the time in 2022

* 39. At your organization what disciplines routinely participate in ACP planning conversations and assisting patients/families/caregivers with completing the forms? Check all that apply.

- Physician
- Advanced Practice Provider - Physician Assistant/Nurse Practitioner
- APRN
- Registered Nurse/Licensed Practical Nurse
- Social Worker
- Chaplain
- Rehabilitation (Physical Therapist/Occupational Therapist)
- Psychiatrists
- Psychologist/Counselor
- Nursing Assistant or Aide
- Pharmacist
- Dietician
- Volunteers
- Other (please specify)

Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Palliative Care Patient Characteristics

* 40. What were the most common conditions or diagnoses seen by your palliative care program in **2022**?

- Cancer
- Blood and bone marrow disorders requiring stem cell transplant
- Heart disease
- Cystic fibrosis
- Dementia
- End-stage liver disease
- Kidney failure
- Lung disease
- Parkinson's disease
- Stroke
- Other (please specify)

* 41. What were the most common symptoms that your organization sought to improve with palliative care services in **2022**? Please list the top 3 most common symptoms.

- Pain
- Nausea or vomiting
- Anxiety or nervousness
- Depression or sadness
- Constipation
- Difficulty breathing
- Anorexia
- Fatigue
- Trouble Sleeping / Insomnia
- Other (please specify)

* 42. How many **pediatric patients** did you provide palliative care services to in **2022**?

- None (0)
- 1-5 pediatric patients
- 6-10 pediatric patients
- 11-15 pediatric patients
- 15-20 pediatric patients
- 20+ pediatric patients

* 43. If you provided **pediatric palliative care** services in **2022**, what percentage of your pediatric clinicians have specialty pediatric palliative care training? Please enter a whole number. If you did not serve the pediatric population, write "Not applicable".



Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Financing Palliative Care

This section does not ask for specific financial numbers from your organization. The results of this survey will not be linked to you or your organization by name in the summary report. Only aggregated summary data by organization type will be included in the summary report.

* 44. Does your palliative care program have adequate financial support from your organization? Provide 1-2 sentences of explanation for your choice of yes or no.

Yes

No

* 45. Does your palliative care program have adequate administrative support from your organization? Provide 1-2 sentences of explanation for your choice of yes or no.

Yes

No

* 46. Which payers or groups do you bill for palliative care services provided by your organization? Check all that apply.

- Medicare
- Medicaid
- Commercial/Private Insurance Payers
- Veteran's Administration
- Patients or Family Members
- Other (please specify)

* 47. Are any of the palliative care services your organization provides covered under a value-based healthcare services contract?

- Yes
- No

* 48. On average, what percentage of your palliative care program revenue comes from the following sources? Please enter 0 or use whole numbers and the total should add up to 100.

Provider Time Services (e.g., Physician time for Medicare Part B or Medicare Fee for Service)	<input type="text"/>
Medicare Part A (Inpatient or facility billing)	<input type="text"/>
Inpatient Billing-Other	<input type="text"/>
Outpatient Billing - E/M Codes	<input type="text"/>
Outpatient billing - Time Based Billing	<input type="text"/>
Outpatient Billing - Medical Decision Making	<input type="text"/>
Telehealth Billing	<input type="text"/>
Hospital or Health Systems RVUs	<input type="text"/>
Non-facility payments for codes for community-based palliative care programs	<input type="text"/>
Value-based health care programs (e.g., ACO participation, CMMI APM participation, other)	<input type="text"/>
Other	<input type="text"/>
Unknown	<input type="text"/>

* 49. Did you use the ICD-10-CM Z-code Z51.5 in any of your billing for palliative care services in **2022**? (Note z-codes are currently not reimbursable, but some programs use z-codes to track the use of palliative care services and/or for quality improvement initiatives.)

- Yes
- No
- Do not know

* 50. Did you utilize and bill for Advance Care Planning (ACP) discussions using the CPT codes 99497 or 99498 in **2022**?

- Yes
- No

* 51. What percentage of your palliative care program expenses were paid for by direct care billing in **2022**? Please utilize a whole number between 0-100.

* 52. Does your program have any other financial support or funding that supports your palliative care program? Check all that apply.

- Donations/Philanthropy
- Grants
- Research programs
- Academic institution support
- Other (please specify)



Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Monitoring Palliative Care Quality and Outcomes

53. Hospitals Only Question

If you are not a hospital, please check "Not applicable".

Indicate which areas your hospital regularly collects or tracks data on for your palliative care program. Check all that apply.

- Not applicable
- Palliative care Services Utilization Rates
- Palliative Care Consultations
- ICU Length of Stay
- Mortality
- Patient Quality of Life
- Hospital/Emergency Department Admission Rates
- Hospital/ED Readmission Rates
- Service Utilization
- Cost saving/Cost Avoidance Practices
- Hospice Referrals
- Quality Improvement Initiatives
- Other (please specify)

54. Community-Based Programs Question

If you are not a **community-based program**, please check "Not applicable".

For community-based palliative care programs (Home Health, Nursing Home, Hospice program) please indicate areas you regularly collect or track data on for your palliative care program. Check all that apply.

- Not applicable
- Hospital readmission rates
- Palliative care services utilization rates
- Mortality
- Patient Quality of Life
- Cost Savings/Cost avoidance practices
- Discharge location(s)
- Other (please specify)

* 55. What metrics or measures does your palliative care program use to track the quality of care being provided or to track success? Check all that apply.

- Patient satisfaction survey
- Monitor the number of completed advanced directives
- Monitor costs and cost saving opportunities
- Monitor and reduce unnecessary hospital readmissions
- Monitor and reduce general hospital admissions
- Monitor and reduce Emergency Department use
- Track the number of hospice referrals
- Track days in hospice for your referrals
- Utilize national guidelines (e.g. National Coalition for Hospice and Palliative Care Clinical Practice Guidelines for Quality Palliative Care) in your program
- Utilize quality measures for public reporting (e.g., Hospice Item Set, AAHPM Feeling Heard and Understood Measure Others)
- Participate in the Hospice Quality Reporting Program
- Participate in the CAHPS Hospice Survey
- Other (please specify)

- None of the above

* 56. Briefly describe any quality improvement projects and performance improvement initiatives your palliative care program or organization is currently participating in or has participated in in the past ?

57. Does your palliative care program participate in any registries or data collection programs with state, regional, national or international groups?

Palliative Care Quality Collaborative Registry (www.palliativequality.org)

Other (please specify)

None of the above

* 58. Has your organization completed any studies or data analyses to assess the impact of your palliative care program on cost, quality or patient satisfaction?

For example, research studies focused on increasing advanced directives, decreasing visits to the Emergency Department, improving cost savings, assessing quality of life, increasing hospice referrals or any other areas.

No

Yes (briefly describe)

* 59. Briefly describe your palliative care program's greatest challenges or barriers to providing palliative care services.

* 60. Briefly describe your palliative care program's greatest strengths or enablers of providing high quality palliative care services.

* 61. Briefly describe what information, education and resources should be available for the public, patients and family/caregivers about the role of palliative care and palliative care services.



Prevalence of Palliative Care in Maryland

2023 MHCC Palliative Care Survey ("Survey")

Thank You

Thank you for your participation in the Prevalence of Palliative Care in Maryland Survey being conducted by SEA Healthcare in partnership with the Maryland Health Care Commission. We sincerely appreciate your time and effort in completing these questions.

* 62. One last question!

Please list the name of the organization, contact person, and email address for any Maryland Palliative Care Programs that we should contact to participate in this Survey or list "none".

We need your help to ensure we are not missing any organizations from our lists.

Thank you again for your participation in the Prevalence of Palliative Care in Maryland 2023 - MHCC Palliative Care Survey. Your time and feedback are greatly appreciated.

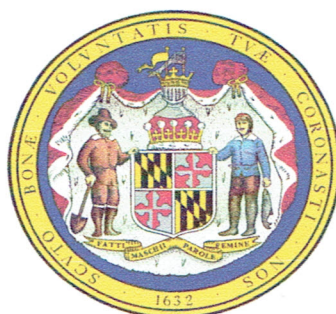
Questions? Please contact Rebecca Swain-Eng, DHSc(c), MS, CAE, Project Lead, SEA Healthcare for any questions or to provide any additional information. rswaineng@swainengassociates.com

APPENDIX E

Palliative Care Hospital Report



Maryland Hospital Palliative Care Programs: Analysis and Recommendations



**Required under HB 581: *Hospitals-Establishment of
Palliative Care Pilot Programs***

December 1, 2015

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Executive Summary

Introduction

Palliative care is specialized medical care for individuals with life-threatening conditions that provides patients with relief from symptoms, pain, and stress in order to improve their quality of life. Palliative care can be provided at any stage in a serious illness or condition and may be provided along with curative treatment. This is in contrast to hospice care which is provided when the patient has a life of six months or less, and agrees to forego any curative treatment. Demand for palliative care services is projected to grow as population demographics continue to skew older and medical advances increase life expectancy. Nationally, the number of palliative care programs in hospitals more than doubled between 2000 and 2010. At least 30 Maryland hospitals developed palliative care specialty services within that same time frame. With the growth of this specialty, steps toward promoting expansion and standardization have recently gained momentum in other states including New York, Rhode Island, Connecticut, Massachusetts, and California.

During the 2013 legislative session, the Maryland General Assembly passed House Bill 581 (HB 581) which directed the Maryland Health Care Commission (the Commission) to collaborate with the Department of Health and Mental Hygiene (DHMH) Office of Health Care Quality (OHCQ) and the Maryland Hospital Association (MHA) on a pilot study of geographically diverse hospital palliative care programs in order to gather data on costs, savings, access, and patient choice, and to report on best practices to be used in the development of statewide standards. With 11 pilot hospitals representing services in nine Maryland jurisdictions and with guidance from the Hospital Palliative Care Advisory Group, the Commission embarked on designing a data collection process, reviewing existing resources and initiatives, and developing recommendations for best practices and minimum standards.

Pilot Study Process

The Commission selected 11 established hospital palliative care programs to participate in the pilot project through a Request for Applications process. A review of academic studies and other publications provided additional insight. Two entities in particular, which are leaders in palliative care and health care research and advocacy, the Center to Advance Palliative Care and the National Quality Forum (NQF), provided materials that were key in the development of both the research design and findings. Responses to surveys were used to develop profiles and compare pilot program structures, staffing, and practices. In order to develop a set of best practices and minimum standards, this project used the NQF's endorsed list of 38 preferred practices for palliative and hospice care programs as a guide for discussion. These practices also serve as the foundation for the Joint Commission on Accreditation for Healthcare Organization's (Joint Commission) certification requirements for palliative care programs. Additionally, pilot hospitals provided detailed data on their patient populations over the course of one fiscal year by flagging consultations in the Health Services Cost Review Commission's (HSCRC) discharge abstract.

Results of the Data Collection

Primary and secondary data provided the basis for a summary of palliative care services across Maryland, a profile of the pilot programs, and a representation of the patient populations at pilot programs during the designated study period. Common program characteristics include: inpatient consultation models; interdisciplinary teams; at least one credentialed staff member; existence of certain policies and plans; and challenges with limited resources, staffing shortages, lack of awareness, and late referrals. The report also includes descriptions of screening processes and services provided at hospitals with palliative care programs in Maryland, as well as each pilot's description of its relationship to hospice services, integration with emergency services, and integration with intensive care services. Only one program in Maryland is currently certified by the Joint Commission, while others reported that they did not believe the benefits outweigh the costs associated with the certification process at this time. Six out of 11 pilots offered outpatient palliative care services. After consultation with the Advisory Group, the Commission determined that this pilot project should focus on the inpatient experience.

The palliative care inpatients flagged during the pilot period had serious, life-threatening diseases and were often near the end of life. Four in 10 patients were referred to hospice as a result of a palliative care consultation. Compared to unflagged medical/surgical inpatient populations at pilots, patients who received palliative care consultations had longer lengths of stays and costly health care stays. Alternatively, average charges per day for patients who received palliative care consultations were lower than average charges per day for unflagged medical/surgical inpatients who did not receive a palliative care consultation. Unfortunately, the impact of the palliative care intervention cannot be fully assessed during a particular hospital stay because it is unknown at what point during the hospital stay the patient received a consultation or accepted palliative care. Additionally, pilots advised that some dying patients stayed in the hospital for an extended period of time, which increased the length of stay while making them prime candidates for palliative care. In order to truly measure the impact of this intervention, which is intended to benefit patients who are likely to need continued medical care throughout the progression of a serious life-threatening disease, total health care system use must be considered. Such research was beyond the scope of this project. More nuanced studies which group pilot hospitals or more detailed patient characteristics could offer additional insight. Both tracking patient utilization across different health care settings and subgrouping the pilot hospitals by common characteristics was beyond the scope of this study, which was to recommend best practices and minimum standards for these programs.

Research Findings

Costs, savings, and benefits of palliative care services

This report provides information on inpatient experience and charges for a single hospital stay. However, it does not include conclusions regarding a direct relationship between a palliative care consultation and patient experience as a result of that consultation or service provision for a number of reasons. It is unknown at what point during the stay a palliative care consultation took place, and, consequently, when a palliative plan of care may have been

accepted which may decelerate a patient's aggressive and costly treatment. There are also significant differences in the in-hospital mortality rate of patients who accepted palliative care at the pilot hospitals, pointing to potential differences in hospital practices for patients near the end of life that also affect this comparison.

While analysis of the primary data collected during the pilot period did not offer a definitive conclusion regarding the comprehensive costs or savings related to palliative care, there are other published studies that reported cost savings. The American Medical Association published a study in 2008 which indicated that palliative care team consultations resulted in savings of nearly \$1,700 in direct costs per admission and \$279 on savings per day for patients discharged alive. For patients who died in the hospital, cost savings were higher – more than \$4,900 per admission and \$347 per patient day. Indeed, the pilot data allows for comparison of flagged palliative care groups who accepted and declined palliative care. The differences in charges per stay between these two groups were in the hundreds and thousands of dollars in some cases. However, due to the reasons listed above, this data cannot be used to conclude a direct relationship between receiving a consultation or accepting palliative care and the outcome of a hospital stay. Further, these comparisons were not consistent across all pilot hospitals.

Other published studies also report reduced readmissions and reduced costs for emergency services as a result of palliative care. Two pilots conducted independent research that indicated patients who accept a palliative care plan of care had lower readmission rates and lower charges during subsequent hospital visits at their hospitals. Additionally, Advisory Group members provided research that indicated patients and caregivers reported a higher level of satisfaction with their hospital experience after a consultation with a trained palliative care team member.

Access to palliative care services and patient choice

Hospitals in Maryland and across the country are increasingly investing in specialized palliative care programs, credentialed staff, and staff training as they begin to recognize the value of this service. At the time of this study, at least 32 hospitals in Maryland had what they consider a palliative care program. Additionally, every general acute care hospital had personnel who delivered some type of palliative care services at that hospital during the study period, based on a specific procedure code for palliative care. Based on surveys of Maryland hospital administrators, at least half of Maryland hospitals will expand their palliative care program and awareness in the near future.

Pilot hospital data suggests that Hispanics receive consultations at a rate that is less than the rate of all medical/surgical admissions. African Americans, though similarly represented in palliative care consultations and general medical/surgical populations, were overrepresented in the proportion of patients who declined palliative care after a consultation. This latter finding is in line with the existing data regarding the lower use of hospice services among African Americans compared to Whites. Recommendations include an emphasis on cultural sensitivity and interpretation services in order to address these concerns.

Evaluation of Best Practices and Minimum Standards

In addition to data collection and analysis to gain further insight into costs, savings, benefits, access, and patient choice, HB 581 directs the Commission to provide recommendations to be used to develop minimum standards for palliative care programs with the goal of expanding access to palliative care services statewide at hospitals with 50 beds or more by July 1, 2016, in a manner that ensures geographic balance and promotes racial and ethnic diversity. In order to develop a list of recommendations that meets this directive, staff consulted with national and local advocates and determined that an existing list of 38 recommended practices, endorsed by the NQF, should serve as a guide for discussion. The Advisory Group reviewed the 38 “preferred practices” in depth. Of those practices, 37 were retained or modified for a list of recommended best practices, and 30 of those were recommended as minimum standards for a hospital palliative care program. The Commission recommends that statewide minimum standards first focus on practices that will ensure an acceptable level of patient care, consistent across hospitals. Then as resources allow, programs should implement best practices to the extent possible.

Recommendations

The Commission, in consultation with OHCQ, MHA, and the Hospital Palliative Care Advisory Group, recommends the following 37 best practices under eight domains, of which 30 are recommended as minimum standards, which are based on the NQF-endorsed 38 preferred practices for hospice and palliative care programs.

Structures of Care: Four best practices, also recommended as minimum standards

- Hospitals should provide palliative care by an interdisciplinary team, trained in palliative care, to consult on palliative care services in collaboration with primary health care professionals.
- Hospitals should provide education to all health professionals on the domains of palliative care.
- Palliative care programs should provide adequate training and clinical support to ensure that professional staff are confident in their ability to provide palliative care for patients.
- Palliative care programs should ensure the palliative care team is appropriately trained, credentialed, and/or certified in their area of expertise.

Processes of Care: Five best practices, also recommended as minimum standards, and one best practice only

- Palliative care programs should record the patient’s palliative care goals, needs, and care plans in medical orders.
- Palliative care programs should ensure timely and thorough transfer of the patient’s goals, needs, and care plans upon transfer to a different care setting.
- Palliative care programs should present hospice as an option to patients and families when appropriate, based on an assessment of the patient’s and family’s goals, needs, and plan of care.

- Palliative care programs should enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.
- Palliative care programs should provide education and support to families and unlicensed caregivers to ensure safe and appropriate patient care with educational materials that are age-, language-, and educationally appropriate.

Best practice only Palliative care programs should ask patients and caregivers to assess the physicians'/health care professionals' ability to discuss hospice as an option.

Physical Aspects of Care: One best practice, also recommended as a minimum standard, and one best practice only

- Palliative care programs should measure and document pain, dyspnea, constipation and other symptoms using available standardized scales.

Best Practice Only Palliative care programs should ask patients and caregivers whether pain, dyspnea, constipation and other symptoms and side effects were managed in a timely, safe, and effective manner to a level acceptable to the patient and family.

Psychological and Psychiatric Aspects of Care: Two best practices, also recommended as a minimum standards, and two best practices only

- Palliative care programs should assess the psychological reactions of patients and families to address emotional and functional impairment and loss, including stress, anticipatory grief and coping. Programs should develop a plan to address the needs of the patient and family and make appropriate referrals for the ongoing management of needs.
- Hospitals should identify resources to address the grief and bereavement care needs for patients and families, within the hospital or through referral to a hospice provider.

Best practice only Palliative care programs should measure and document anxiety, depression, delirium, behavioral disturbances and other common psychological symptoms using available standardized scales.

Best practice only Palliative care programs should ask patients and caregivers whether the patient's anxiety, depression, delirium, behavioral disturbances and other psychological symptoms were managed in a timely, safe, and effective manner to a level acceptable to the patient and family.

Social Aspects of Care: Two best practices, also recommended as minimum standards

- Palliative care programs should conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis and advance care planning, and offer support.
- Palliative care programs should develop and implement a comprehensive social care plan that addresses social, practical, and legal needs of the patient and caregivers.

Spiritual, Religious, and Existential Aspects of Care: Two best practices, also recommended as minimum standards, and two best practices only.

- Palliative care programs should provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
- Palliative care programs should develop an ongoing relationship with spiritual care professionals in order to educate spiritual care professionals about palliative care issues and concerns.

Best practice only Palliative care programs should develop and document a plan based on assessment of religious, spiritual, and existential concerns using a structured instrument and integrate the information into the palliative care plan.

Best practice only Palliative care programs should build partnerships with community clergy and provide education and counseling related to end-of-life care.

Cultural Aspects of Care: Two best practices, also recommended as minimum standards

- Palliative care programs should conduct a cultural assessment of the patient's needs as a component of that patient's plan of care.
- Hospitals should have interpreter services available at the hospital, and palliative care programs should utilize these services as needed.

Care of Imminently Dying Patient: Six best practices, also recommended as minimum standards

- Palliative care programs should recognize and document the transition to the active dying phase and communicate to the patient, family and staff the expectation of imminent death.
- Palliative care programs should educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate and culturally appropriate manner.
- Palliative care programs should routinely ascertain and document patient and family wishes about the care setting for site of death, and fulfill patient and family preferences when possible.
- Palliative care programs should provide adequate dosage of analgesics and sedatives to achieve patient comfort and address concerns about narcotics and analgesics hastening death.
- Hospitals should have a plan or policy to treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.
- Hospitals should facilitate effective grieving by implementing a bereavement care plan in a timely manner after the patient's death through services provided at the hospital or develop a relationship with another provider, such as a hospice, for these services.

Ethical and Legal Aspects of Care: Six best practices, also recommended as minimum standards, and one best practice only

- Hospitals should document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
- Palliative care programs should document the patient/surrogate preferences for goals of care, treatment options and setting of care at first assessment and at frequent intervals as conditions change.
- Hospitals should convert the patient's treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services and hospital care, by using the MOLST program to the fullest extent possible and ensuring that staff is trained and knowledgeable of the benefits.
- Hospitals should make advance directives and surrogacy designations available in electronic personal health records.
- Hospitals should develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals.
- Palliative care programs should have access to or establish ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.

Best practice only Palliative care programs should develop a relationship with a provider who specializes in pediatric palliative care.



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Health Care
Commission

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