Original Article

An Assessment of Hospital-Based Palliative Care in Maryland: Infrastructure, Barriers, and Opportunities

Kenneth D. Gibbs Jr., PhD, MPH, Margaret M. Mahon, PhD, CRNP, Meredith Truss, MPP, and Kira Eyring, BS
Cancer Prevention Fellowship Program (K.D.G.), Division of Cancer Prevention; Science of Research and Technology Branch (K.D.G.), Behavioral Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, Maryland; University of Maryland Medical Center (M.M.M.), Baltimore, Maryland; Maryland Department of Health and Mental Hygiene (M.T.), Baltimore, Maryland; and American Cancer Society (K.E.), Atlanta, Georgia, USA

Abstract

Context. Maryland recently passed legislation mandating that hospitals with more than 50 beds have palliative care (PC) programs. Although the state’s health agency can play a key role in ensuring successful implementation of this measure, there is little actionable information from which it can guide resource allocation for enhancing PC delivery statewide.

Objectives. To assess the PC infrastructure at Maryland’s 46 community-based nonspecialty hospitals and to describe providers’ perspectives on barriers to PC and supports that could enhance PC delivery.

Methods. Data on PC programs were collected using two mechanisms. First, a survey was sent to all 46 community-based hospital chief executive officers by the Maryland Cancer Collaborative. The Maryland Health Care Commission provided supplementary survey and semistructured interview data.

Results. Twenty-eight hospitals (60.9%) provided information on their PC services. Eighty-nine percent of these hospitals reported the presence of a structured PC program. The profile of services provided by PC programs was largely conserved across hospital geography and size. The most common barriers reported to PC delivery were lack of knowledge among patients and/or families and lack of physician buy-in; most hospitals reported that networks and/or conferences to promote best practice sharing in PC would be useful supports.

Conclusion. Systematic collection of state-level PC infrastructure data can be used to guide state health agencies’ understanding of extant resources and challenges, using those data to determine resource allocation to promote the timely receipt of PC for patients and families. J Pain Symptom Manage 2015;49:1102–1108. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words
Palliative care, infrastructure, state-level data, barriers and supports, departments of health

Introduction

In 2013, the Maryland legislature passed, and the governor signed into law, House Bill 581.1 This law requires that by 2016, Maryland hospitals with 50 or more beds have an accredited palliative care (PC) program, and all hospitals provide access to information and counseling regarding PC services appropriate to a patient with a serious illness or condition. Research has identified multiple benefits of timely integration of PC for patients, caregivers, and health care systems.2 Randomized trials have shown that for patients facing serious illnesses, early integration of PC (concurrent with standard and disease-focused care) is associated with equivalent or improved survival, decreased symptom burden, enhanced satisfaction with treatment experience, better symptom management, and improved quality of life for caregivers.3–8 Furthermore, for patients with life-threatening
illnesses (e.g., cancer, chronic obstructive pulmonary disease, stroke), early receipt of PC resulted in fewer hospital days and average health care costs roughly $4800–$7500 less than patients receiving standard care alone.9,10

Despite the benefits of timely receipt of PC, evidence suggests that it remains underused.11–13 Potential clinical barriers include physician attitudes,14 avoidance of palliative and end-of-life discussions until all treatment options have been exhausted,15 and a lack of knowledge by providers about the types of services available through PC, patient eligibility, and best time to initiate referrals.16 Organizational barriers also can present hurdles to broader integration of PC as facilities that serve chronically ill patients sometimes lack sufficient numbers of appropriately trained staff, adequate resources, and protocols to optimize the chances of timely receipt of PC.17,18

In addition to ensuring compliance with House Bill 581, Maryland’s state health department (i.e., the Department of Health and Mental Hygiene [DHMH]) is well positioned to coordinate resources and catalyze systemic changes that can ultimately enhance access to PC statewide. The ability for DHMH to do this depends on the availability of timely actionable information. Previous work has examined the availability of PC services nationwide at cancer centers,19 but there remains a gap in understanding PC availability and barriers at the state and local levels. This study aims to address some of these gaps at the state level and is centered on the following questions:

1. What is the hospital-based PC infrastructure in the state of Maryland? That is, how widely available is PC, and what types of services do PC programs offer?
2. What PC services do hospitals plan to enhance over the next five years?
3. From the provider perspective, what are barriers to enhanced delivery of PC, and what are useful supports that would enhance PC delivery?
4. To what extent do the infrastructure, barriers, and supports differ based on hospital size or region?

**Methods**

**Survey Design**

A review of existing PC surveys19,20 was conducted by the Palliative Care Workgroup of the Maryland Cancer Collaborative, a statewide coalition supported by the Maryland DHMH, which works to implement the Maryland Comprehensive Cancer Control Plan. Questions were developed by the workgroup with the input of external experts, including members of the Maryland Cancer Collaborative Evaluation Workgroup, the Maryland State Council on Cancer Control, the Maryland State Advisory Council on Quality Care at the End of Life, and the Hospice and Palliative Care Network of Maryland. Questions were developed to collect data around several focus areas: PC processes, PC program characteristics, PC program staff, temporal trends in PC, and challenges and needs.

During the survey revision process, the Maryland Cancer Collaborative became aware of a survey and semistructured interviews that were conducted during the fall of 2013 by the Maryland Health Care Commission (MHCC), another division of the DHMH. The collaborative partnered with the MHCC and adapted the wording of several survey questions to match questions asked by the MHCC to collect comparable data.

**Data Collection**

Surveys were distributed to all nonspecialty community-based hospitals in Maryland. Given the assumption that PC services may be coordinated by various hospital departments, rather than attempting to identify and send to the appropriate contact within each hospital, surveys were sent to hospital chief executive officers (CEOs). An introductory letter was mailed to each CEO with a request for the CEO to designate the appropriate PC contact at the institution to complete the survey instrument online. A fact sheet about PC also was mailed with the letter to raise awareness of the benefits of providing hospital-based PC among CEOs. Copies of the surveys and other materials are provided in the Appendix (available at jpsmjournals.com). Responses were compared with data collected by the MHCC; responses of hospitals that had already reported data through the MHCC survey data were merged for matched questions.

Within three weeks after the initial mailing, CEO assistants were contacted by phone and/or electronic mail to collect contact information of the designated responder. Third and fourth contacts were attempted for more than eight weeks to remind nonresponders and encourage survey completion. Hospitals were considered nonresponders if they did not complete the survey after four attempted contacts.

**Statistical Analysis**

Fisher’s exact test was performed to compare all survey responses based on hospital size (i.e., 250 beds or fewer vs. more than 250 beds) and region (i.e., Central Maryland vs. Western Maryland, Southern Maryland, and the Eastern Shore). All analyses were performed using GraphPad Prism (GraphPad Software, Inc., La Jolla, CA), and figures were made using Adobe Illustrator (Adobe Systems Inc., San Jose, CA).
**Results**

**Maryland Hospitals and Response Rate**

Basic information on the PC infrastructure was received from 28 of 46 Maryland hospitals. This included 25 that provided extensive information by completing the full survey (survey response rate 54.3%) and three additional hospitals that provided basic information through the MHCC survey. These 28 hospitals had a total of 8263 hospital beds, representing 80% of all hospital-based and licensed acute care beds in the state. The 25 hospitals completing the full survey had a total of 7007 hospital beds, representing 67.7% of hospital beds in the state.21 A comparison of responding and nonresponding hospitals is shown in Table 1.

Responding hospitals were diverse with respect to size and geographic distribution. Slightly more than half of the hospitals had 250 beds or fewer (n = 15; 53.6%), and the remainder were larger hospitals with more than 250 beds (n = 13; 46.4%). Most hospitals in the sample were from Central Maryland (n = 15; 53.6%); the remaining were from Southern Maryland (n = 6; 21.4%), Western Maryland (n = 5; 17.9%), and the Eastern Shore (n = 2; 7.1%). Hospitals that provided data had an average of 295 licensed acute care beds per facility compared with 97 beds per facility for nonresponders.19 Most nonresponsive hospitals were small to medium in size; 13 of 18 nonresponders had less than 250 beds.19 Nonresponders were distributed across geographic regions, with seven located in Southern Maryland, six in Central Maryland, and five in the Eastern Shore region. There were no statistically significant differences in hospital size (dichotomized as more or less than 250 beds) or hospital geography (dichotomized as Central Maryland vs. other region) in the responding and nonresponding hospitals (P > 0.2).

### Table 1

**Characteristics of Maryland Hospitals**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Respondents, n (%)</th>
<th>Nonrespondents, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number</td>
<td>28</td>
<td>18</td>
</tr>
<tr>
<td>Number (%) with PC program</td>
<td>25 (89)</td>
<td>—</td>
</tr>
<tr>
<td>Percent of hospital-based licensed acute care beds in state</td>
<td>80</td>
<td>20</td>
</tr>
<tr>
<td>Number of hospital beds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–50</td>
<td>1 (3.6)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>51–100</td>
<td>3 (10.7)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>101–200</td>
<td>2 (7.1)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>201–250</td>
<td>9 (32.1)</td>
<td>4 (22.2)</td>
</tr>
<tr>
<td>251–300</td>
<td>7 (25)</td>
<td>1 (5.5)</td>
</tr>
<tr>
<td>301+</td>
<td>6 (21.4)</td>
<td>4 (22.2)</td>
</tr>
<tr>
<td>Hospital region</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Central Maryland</td>
<td>15 (53.6)</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td>Southern Maryland</td>
<td>6 (21.4)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Western Maryland</td>
<td>5 (17.9)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Eastern Shore</td>
<td>2 (7.1)</td>
<td>5 (27.8)</td>
</tr>
</tbody>
</table>

PC = palliative care.

**Hospital-Based PC Infrastructure in the State of Maryland**

Of the 28 hospitals responding, 25 (86.2%) reported the presence of a PC program, that is, a structured hospital-based program that employs a multidisciplinary team that may include doctors, nurses, and other specialists who work together with a patient’s other health care providers to provide PC, and three hospitals (13.8%) reported no PC program (Table 1). Overall, 54% of hospitals reported programs that provided inpatient PC only; 32% of hospitals reported programs that provided both inpatient and outpatient PC (Table 1). Thus, although most hospitals reported the presence of a PC program, less than a third of the hospitals reported having programs that provided outpatient PC.

Of the 25 PC programs, only one reported Joint Commission certification in PC, although five reported that they were in the process of applying for certification, or planned to do so within the next 24 months. Staffing issues represented the most common barrier to certification, with eight hospitals indicating this as a challenge. Specifically, these hospitals indicated the need for 24/7 coverage, difficulty finding qualified personnel, and the need for additional full-time staff among the barriers that prevent them from pursuing certification. Other common barriers to pursuing certification included the newness of the program (four programs), the high costs associated with certification (three programs), and the lack of clear benefits for pursuing certification (three programs).

**Characteristics of PC Programs: Services Provided and Process for Initiating PC**

The hospital-based PC programs were asked to provide information on the types of services provided and their process for initiating PC (Table 2). PC services provided were similar across hospital size and geography. More than 80% of programs reported the presence of nine of the 11 PC program characteristics assessed. These services included bridging patients to hospice care (100%), pain and/or symptom assessment and management (95%), discussion of advance directives with patients (95%), psychosocial support (91%), preparation of a comfort care plan (91%), pastoral care/spiritual consultation (86%), bridging to community resources (86%), and caregiver/family support (81%). In contrast, 59% of hospitals reported discussion of financial planning or referral to financial counselors as part of their PC programs, and 54.5% indicated that psychiatric and mental health assessment and management was a service provided by their PC program, indicating potential areas for improvement in the PC infrastructure. With the exception of financial planning services, which were present not only in 38.5% of PC programs in Central Maryland
but also in 88.9% of PC programs in other regions ($P = 0.03$), there were no statistically significant differences in the representation of any of these 11 program characteristics by region (Central Maryland vs. Southern Maryland/Western Maryland/Eastern Shore) or hospital size (250 beds or fewer vs. greater than 250 beds).

In addition to PC services, survey respondents also provided information regarding the process and personnel responsible for initiating discussions about PC with patients—information valuable to determining potential areas where intervention can lead to expanded PC services for patients who could benefit. Within PC programs, the most common mechanisms for initiating discussions with patients were “at the request of the health care provider” (91%) and “at the request of the patient or family” (82%) (Table 2). Fifty-five percent of hospitals reported that PC discussions are initiated when patients are diagnosed with conditions that may require PC, and 18% of hospitals indicated that the PC discussions are initiated during the first treatment appointment (for cancer or other conditions). Accounting for hospitals that used both mechanisms (appropriate diagnosis or initial treatment) for initiating PC discussions, 13 of the 22 PC (59%) programs for which there was extensive information indicated that PC discussions are systematically initiated early in the course of treatment for conditions that may require PC. In contrast, 18% of hospital PC programs indicated that their institution does not have a formal process to initiate PC discussion. When asked who can initiate a referral for a PC consultation at the institution, 95% of institutions indicated physicians, and 86% of institutions responded that midlevel providers (e.g., physician assistants and advanced practice registered nurses) could initiate these referrals (Table 2). Social workers and nurses were able to initiate referrals for PC consultation at a minority of institutions (36% and 32%, respectively).

**Plans for PC Program Expansion**

Hospitals also were asked about whether they planned to add or increase PC services in the coming three years (Table 3). Sixty-four percent of hospitals planned to increase the number of PC physicians, nurses, and/or physician assistants; 56% indicated that they planned to add or expand educational opportunities, training, or professional development in PC for employees. Fewer than half of institutions plan to increase their budget for PC (48%) or add or increase the number of nonmedical PC team members such as social workers or chaplains (44%), and none reported intentions to add or increase the number of PC acute beds (0%). Three hospitals (12%) planned to establish a PC program within the next three years, including one of the four hospitals surveyed that does not have a PC program currently, and two hospitals with relatively new PC programs; presumably these two hospitals will further establish their new programs.

**Barriers to Offering PC at Institutions**

Respondents were asked to identify challenges to providing PC at their institution (Table 3). The most common barriers reported were lack of knowledge about PC among patients and/or families (68%), lack of physician buy-in (56%), limited budget...
Challenges to providing PC at institution

Although there were no regional differences in the distribution of these barriers, smaller hospitals (i.e., 250 beds or fewer) were more likely to indicate that limited budget for PC represented a barrier (16%), lack of readily available training opportunities (12%), few referrals (12%), limited PC needs (8%), and concern that PC may increase hospital mortality (8%).

Useful Supports Related to PC

Responding CEOs also were asked to identify supports for PC at their institution (Table 3). Sixty-four percent identified best practice sharing from other programs and/or hospitals, whereas 60% of respondents identified participation in a network of other PC professionals and conference on PC best practices as useful. Just under half of the respondents (48%) indicated that reimbursement and/or billing guidance would be useful, and additional potentially beneficial supports included clinical team training (24%), mentor and/or consultation from other programs and/or hospitals (24%), and technical assistance in the development of PC programs (20%). There were no statistically significant regional or hospital size-based differences with respect to the supports that would be useful with one exception. Regarding technical assistance in the development of PC programs, 38% of small hospitals believed that this would be a helpful support, whereas none of the large hospitals (0%) indicated that it would be helpful (P = 0.04).

Discussion

Despite significant evidence that early integration of PC alongside disease-focused therapies can lead to equivalent or improved survival, enhanced quality of life for patients and caregivers, and lower costs to the health care system,6,9,10,22 PC remains underused.11–13 In Maryland, there is a legislative mandate for enhancing PC delivery set to take effect in 2016;1 however, comprehensive information on the state of PC in Maryland remains lacking. This study presents data on the hospital-based PC infrastructure in the state of Maryland and provides important information for understanding how the state health agency (DHMH) can allocate resources with the goal of optimizing PC resources for patients throughout Maryland. Furthermore, it provides a model and point of comparison for other health agencies seeking to enhance PC in their jurisdictions.

The survey responses provided a number of potential areas—structurally, with health care professionals, and with the general public—where interventions could lead to enhanced receipt of PC for patients who would benefit. The vast majority of hospitals sampled (89%) had PC programs, and the service...
profiles were largely similar across geography and hospital size. However, only a minority of hospitals (32%) had outpatient PC services. Outpatient PC services can save costs—with a decrease in emergency department utilization, as well as decreased hospital admissions—and improve improved end-of-life care relative to those receiving inpatient care. Thus, enhancing the outpatient PC infrastructure represents an area that could improve the delivery and receipt of PC throughout the state.

The survey also indicated that systems to ensure timely receipt of PC are far from universal. Although most (59%) PC programs indicated that discussions about PC are initiated at time of diagnosis or at initial treatment for serious illnesses, 41% did not indicate procedures for ensuring timely PC delivery. Health care providers, specifically physicians, were the most likely to initiate discussions with patients about PC; however, lack of physician buy-in was one of the most common challenges to provision of PC at Maryland hospitals. Therefore, enhancing training opportunities to increase physician understanding of PC and/or modifying incentive structures could reverse this perceived lack of support and could enhance timely receipt of PC. Additionally, lack of knowledge about PC among patients and families represented the most common barrier to delivery at Maryland hospitals. Sixty-eight percent of hospitals identified lack of patient knowledge as a barrier, a number in line with national surveys showing 70% of American adults lacked knowledge about what PC is. This suggests that awareness campaigns—either to the general public or targeted in health care settings—could enhance patient knowledge to mitigate this barrier.

The results also suggest that coordination by DHMH could help hospitals in their development or expansion of PC programs. Most hospitals sampled indicated that supporting mechanisms to enhance information sharing among hospitals and PC providers (e.g., conferences or formalized networks) would be helpful to them in optimizing PC delivery. Additionally, small hospitals (in contrast to larger hospitals) noted that technical assistance in the development of PC programs would be a beneficial support.

**Limitations**

There are a number of limitations to the study. First, we were not able to get complete information from all hospitals in Maryland. Additionally, all data relied on self-report. As there was no independent verification of the information provided, this presents the opportunity for bias. Moreover, there are no clear and uniform standards on what constitutes a PC program. Finally, although addressed to hospital CEOs, in some cases, delegates filled out the survey.

**Conclusion**

Although there have been calls to enhance the timely receipt of PC, the role that state health agencies can play has been inconsistently defined and underappreciated. With their broad reach and prominent role in health policy, health departments are well positioned to coordinate resources and catalyze systemic changes that can ultimately enhance the effectiveness of public health initiatives. In Maryland, the DHMH will use the information gathered through this survey to guide its efforts to ensure successful implementation of the universal PC measure set to take effect in 2016. Furthermore, this information provides a baseline that can be used to evaluate the efficacy of policy interventions designed to enhance timely receipt of PC.

**Disclosures and Acknowledgments**

This work was supported by Centers for Disease Control and Prevention Cooperative Agreement Number 5U58DP003919—02. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention. Dr. Gibbs is supported by the Cancer Prevention Fellowship from the National Cancer Institute. This work was completed while Dr. Gibbs was a Master of Public Health candidate at the Johns Hopkins Bloomberg School of Public Health. The authors declare no conflicts of interest.

The authors thank Norma Kanarek and Marie Diener-West for critical review of the article.

**Supplementary Data**

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.jpainsymman.2014.12.004.

**References**


