Hospital-Based Palliative Care Programs in Delaware: An Assessment of Structure, Challenges, and Opportunities

Introduction

Although palliative medicine offers high-quality patient centered care consistent with health reform efforts, there has been no systematic collection of state-level palliative care data in Delaware that could be used to better understand how palliative care could be expanded statewide, or how timely receipt of palliative care services for patients and their families could be promoted.

This study aims to address the knowledge gap in the provision of hospital based palliative care services in Delaware. The study is centered on a number of key questions: How widely available is palliative care in Delaware? What types of services do palliative care programs offer? How will palliative care services grow in the future? What are the barriers to enhanced palliative care delivery? Does hospital size and geography matter?

Survey Design & Data Collection

Delaware Healthcare Association staff reviewed palliative care surveys from other states to create a general framework for the Delaware survey. Staff selected a survey conducted by the Maryland Cancer Collaborative. Maryland's survey collected data around processes, program characteristics, staff, trends, challenges and needs.

The Delaware Healthcare Association's Palliative Care Council, a statewide collaborative representing hospitals, hospice, nursing homes, and physicians, revised the Maryland survey to gather information on, pediatric palliative care services; program certification; education and training efforts; and legislative or reimbursement barriers.

Surveys were distributed to all non-profit hospitals in Delaware. A letter was sent to each CEO asking them to designate the appropriate contact at the institution to complete the survey online via Survey Monkey.

Characteristics of Responding Hospitals

All of Delaware's nonprofit hospitals responded to the PC survey within one month of the request.

Together these hospitals have a total of 2,087 inpatient hospital beds and _____inpatient admissions in 2014. All three Delaware counties are represented in the survey.

# of Hospital beds	# of Respondents
50-100	2
101-200	2
201-300	3
301 – 400	0
400+	1

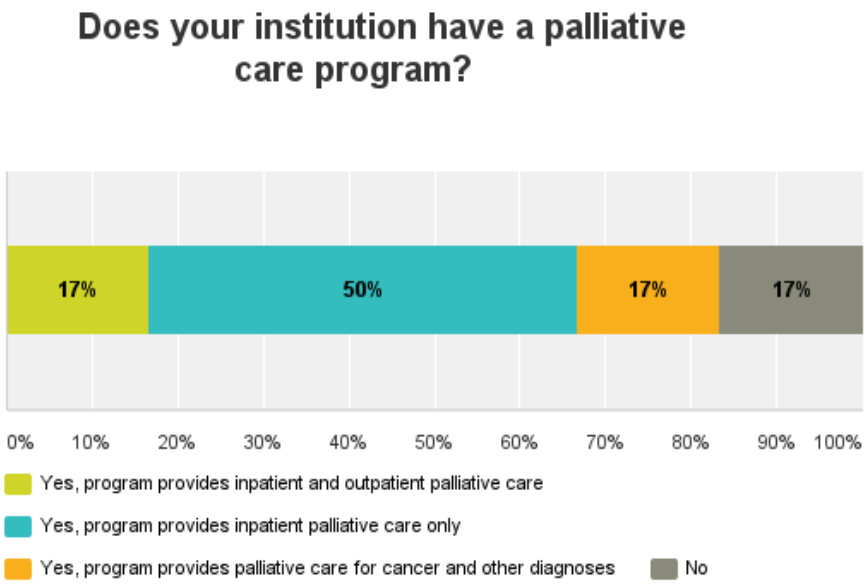
Hospital Region	
New Castle County	4
Kent County	1
Sussex County	3

Palliative Care Program Infrastructure

Two hospital systems and thee hospitals reported the presence of a palliative care (PC) program, meaning 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 healthcare providers to provide palliative care. One hospital reported having no PC program at this time (Figure 1).

Of those hospitals providing a PC Program, 3 hospitals reported an inpatient PC program; 1 hospital reported an inpatient and outpatient PC program; and one reported having a PC program for cancer and other diagnoses. Two hospitals reported a pediatric specific PC program.

Figure 1



None of the PC programs are Joint Commission certified, although most hospitals indicated that they would eventually seek certification. The most common barriers to certification include staffing challenges, lack of financial resources associated with certification, and newness of program. More specifically, hospitals cited the Joint Commission's 24/7 coverage requirement as the biggest hurdle to overcome, followed by the need for additional full-time staff.

Although none of the PC programs are Joint Commission certified, one hospital system and one hospital have registered with the Center to Advance Palliative Care's National Registry, which has a two-fold goal to assist hospital palliative care services in tracking their development year-to-year, and to promote standardization and improve the quality of palliative care in the United States.

Hospital based PC programs are most often led by a physician (60%) or an advanced practice registered nurse (40%). Other staff rounding out hospital palliative care teams include: registered nurses (2 hospitals); clinical social worker/social worker (3 hospitals); chaplain (4 hospitals); dietitian (1 hospital); pharmacist (1 hospital); patient advocate (2 hospitals). Physicians, nurses, and clinical social workers who are part of a hospital's PC team are certified in hospice and palliative care medicine.

While most PC staff are full-time hospital employees, they are not necessarily dedicated as full-time employees in the hospital's palliative care program, meaning that, PC staff in some hospitals have other responsibilities, in addition to serving as an integral member of the PC team.

With respect to provider training and education, 80% of hospitals with a PC program provide staff with PC training. One hospital offers a 16-week orientation session for nurse practitioners and a 6-week training program for social workers. Another hospital conducted a needs assessment and designed in-service and on-line training around the needs assessment findings.

Similarly, 80% of hospitals with a PC program provide training or information about the PC program to others in the community who are not part of the PC program through a variety of community outreach programs.

Process for Initiating Palliative Care Discussions

Survey respondents were asked to provide information regarding the process and personnel responsible for initiating PC discussions with patients (Table 1). Overwhelmingly, the most common ways for initiating discussions with patients were "at the request of the health care provider" (80%) or "at the request of the patient and family"(80%). Initiation also occurs when a patient is diagnosed with a condition that may require palliative care (i.e. cancer) (40%). Only one hospital indicated it initiates PC discussions with patients as early as possible, often when the patient is admitted to the hospital.

When asked who can initiate a referral for a PC consultation at the hospital, 100% of survey respondents indicated physicians; 80% indicated mid-level providers (physician assistants, advanced practice registered nurses); 20% indicated nurses; and another 20% indicated clinical social workers could initiate a referral for PC services. One hospital indicated that a patient or the patient's family could initiate the PC referral.

Table 1

What is the process at your institution for initiating a palliative care consult? Please select all that apply.

Answer Choices	Responses	
Discussed when patients are admitted to the hospital	20%	1
Discussed when patients are diagnosed with a condition that may require palliative care	40%	2
Discussed at the request of the health care provider	80%	4
Discussed at the request of the patient or family	80%	4
Other (please specify)	40%	2
Total Respondents: 5		

Program Services Provided

PC services provided were similar across hospital size and geography. 100% of hospitals with a PC program have at least 4 of 11 PC program characteristics assessed (Table 2). Those 4 characteristics include: preparation of a comfort care plan; pastoral care and/or spiritual consultation; psychosocial support; and caregiver/family support.

Additional PC services provided by at least 4 of 5 (80%) hospitals include symptom assessment and management; pain assessment and management; bridging to hospice care; and discussion of advance directives. Three hospitals reported bridging to community resources and services through their social work departments. Two hospitals discuss financial planning or referral to financial counselors with PC patients, and only 1 hospital provides psychiatric and mental health assessment and management as part of its PC program.

Most hospital PC programs (80%) collaborate with community partners, usually hospice organizations, to provide PC patients with a continuum of services.

Table 2

Which of the following palliative care services does your program currently offer to patients who have been diagnosed with a serious condition or illness? Please select all that apply.

Answer Choices	Responses	
Preparation of a comfort care plan	100%	5
Pastoral care and/or spiritual consultation	100%	5
Psychosocial support	100%	5
Caregiver/family support	100%	5
Symptom assessment and management	80%	4
Pain assessment and management	80%	4
Bridging to hospice care (referral, inpatient, and/or home hospice)	80%	4
Discussion of advance directives	80%	4
Bridging to community resources and services	60%	3
Discussion of financial planning or referral to financial counselors	40%	2
Other (please specify)	40%	2
Psychiatric and mental health assessment and management	20%	1
Total Respondents: 5		

Program/Outcome Measurements

Data collection efforts were assessed to determine how each hospital measures PC program outcomes (Table 3). All hospitals with a PC program are tracking the number of patients encountered and the disposition of patients at discharge. A few hospital PC programs track readmissions data, and track the number of advance health care directives documented in patient records. Measurements targeting satisfaction with PC services (provider, patient, family) are collected by less than half of hospitals surveyed. One hospital collects data around patient experience with pain control and distress.

Table 3

Please indicate whether your institution collects any of the following outcome measures on your palliative care program. Please select all that apply.

Answer Choices	Responses	
Number of patient encounters	100%	5
Disposition of patients at discharge	100%	5
Readmissions data	60%	3
Number of Advance Health Care Directives and/or goals of care discussions that are determined and documented in patients records	60%	3
Other (please specify other outcome measures that your institution collects, and/or provide a summary of outcomes).	60%	3
Mortality data	40%	2
Referral provider satisfaction	40%	2
Patient satisfaction	40%	2
Palliative care provider satisfaction	20%	1
Family satisfaction	20%	1
Reports of effective pain control	20%	1
Decrease in patient distress	20%	1
Total Respondents: 5		

Plans for PC Program Expansion

Hospitals were asked if they plan to add or increase palliative care components within the next three years. 100% of survey respondents said their institutions would increase the number of palliative care physicians, nurses, and/or physician assistants, while 83% said they would increase the number of other members on the palliative care team (social worker, chaplain, etc.).

Increasing educational opportunities, training, or professional development in palliative care for employees also ranked high among survey respondents, with 83% indicating provider education needed to be increased within the next 3 years.

Fewer hospitals (67%) reported funding or budget increases within the next few years. Even fewer hospitals (33%) hope to establish an outpatient palliative care

program within three years. Lastly, one hospital reported they would have a PC program in place within the next few years.

Challenges to Offering Palliative Care at Hospitals

The most common challenge reported across all hospitals was lack of knowledge about PC programs among patients and family (83%) (Table 4).

Other barriers reported among most hospitals included limited budget for palliative care services; lack of adequately trained palliative care staff; and lack of knowledge and understanding of palliative care services offered.

Half of survey respondents reported other barriers such as patients/families are knowledgeable about palliative care, but not interested; poor reimbursement for palliative care services; and lack of buy-in from physicians.

Other less common barriers to increasing palliative care services included lack of buy-in from institution leadership; lack of referrals; lack of palliative care training opportunities; concern that palliative care may increase hospital mortality; and lack of meaningful data collection efforts. Neither hospital size nor geography had any impact on survey responses regarding challenges.

Table 4

What are some challenges to offering palliative care at your institution now or in the future? Please select all that apply.

Answer Choices	Responses	
Patients and/or families are not knowledgeable about palliative care	83%	5
Limited budget for palliative care services	67%	4
Lack of adequately trained palliative care physicians, nurses, social workers, others	67%	4
Staff lacks knowledge and understanding of palliative care services offered at my institution	67%	4
Patients and/or families are knowledgeable but not interested in palliative care	50%	3
Poor reimbursement for palliative care services	50%	3
Lack of buy-in from physicians	50%	3
Palliative care training opportunities for existing team members are not readily available	33%	2
Palliative care is available at my institution but there are few referrals	17%	1
Lack of buy-in from institution leadership	17%	1
Lack of evidence to suggest palliative care improves patient outcomes	17%	1
Concern that palliative care may increase hospital mortality	17%	1
Data collection	17%	1
Total Respondents: 6		

Useful Supports Related to Palliative Care

When asked what supports related to palliative care would be useful, hospitals responded with mixed answers. Most thought participation in a network of other palliative care professionals and best practice sharing from other programs to be most useful (67%). To the latter point, half of respondents indicated a need for a conference on palliative care best practices. Other useful supports included mentor/consultation from other programs (33%); better training for clinical team (33%); reimbursement guidance (33%); and technical assistance in the development of a PC program (17%). Hospital size appeared to affect responses with smaller hospitals reporting a greater need for technical assistance, training, and mentor/consultation from other hospitals.

Discussion

This study presents comprehensive information on the state of hospital-based palliative care in Delaware, and provides useful information that could be utilized to increase PC education and services statewide. Survey responses revealed a number of potential opportunities where interventions could lead to increased receipt of palliative care for patients who would benefit. Those opportunities include:

- A majority of hospitals reported having a palliative care program. However, only one hospital reported having an outpatient PC program. Early outpatient PC referrals would reduce in-patient hospital stays, readmissions, and emergency room visits. Therefore, enhancing the outpatient PC infrastructure could improve the delivery and receipt of PC statewide.

- Universal adoption of timely referral to PC services appears slow. Survey results indicated overwhelmingly that healthcare providers – most often the physician – initiate discussions about PC. Yet, 67% of hospitals indicated that lack of adequately trained palliative care physicians, nurses, social workers, and others are barriers to increasing palliative care services. Physician buy-in was also identified as a barrier by 50% of the hospitals. This suggests more robust education and training opportunities are needed to increase physician and staff understanding of and appreciation for palliative care, and to reverse the apparent lack of support among some providers for PC services.

- Survey results also indicated that patients and their families initiate palliative care discussions nearly as often as healthcare providers. Interestingly enough, 83% of hospitals reported that their biggest challenge to increasing PC services is that patients and/or families are not knowledgeable about palliative care. A statewide awareness campaign targeted to the general public or targeted specifically in healthcare settings could mitigate this barrier by equipping patients with accurate, evidence based information about PC services.

- Expanding access to PC will be limited if reimbursement for non-hospice PC services remains poor – a challenge noted by at least half of survey respondents. Reimbursement for professional consultation with a PC doctor or APRN is the only guaranteed billing for palliative care in the hospital setting. Changes are needed throughout the insurance industry to

incentivize provision of comprehensive palliative care. New models of reimbursement such as bundled payments and medical homes, both being tested under the ACA, may provide an opportunity for increasing PC reimbursement, thereby increasing access to PC services.

- Supporting information sharing among hospitals and PC providers through networking and conferences would help all hospitals optimize PC delivery. Two organizations that could help coordinate such efforts may be the Medical Society of Delaware or the Delaware Academy of Medicine. Additionally, smaller hospitals noted that technical assistance in developing their PC program along with training and mentoring from more established PC programs would be a beneficial support.

- Growth in palliative care programs should not be seen as limited to the hospital setting; the next growth phase will require integration into nursing homes, assisted living, physician practices, and home care.

Conclusion

Nationally and in Delaware, hospitals are increasingly adopting palliative care programs for a number of reasons, most importantly, to improve the quality of life for seriously ill patients who have ongoing acute and long-term care needs and are not predictably dying. As Delaware's population living with serious illness continues to grow, and hospitals treat more chronically ill patients, palliative care programs become an obvious choice. The survey information is a guide, or benchmark, for institutional and policy efforts to increase access to palliative care services, and enhance timely receipt of those services for those patients who would benefit.