



C-Change

**Assessing Palliative/End of Life Care and Hospice Care
In Your Region/State or Community**

By

The Grant Group, LLC

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Introduction

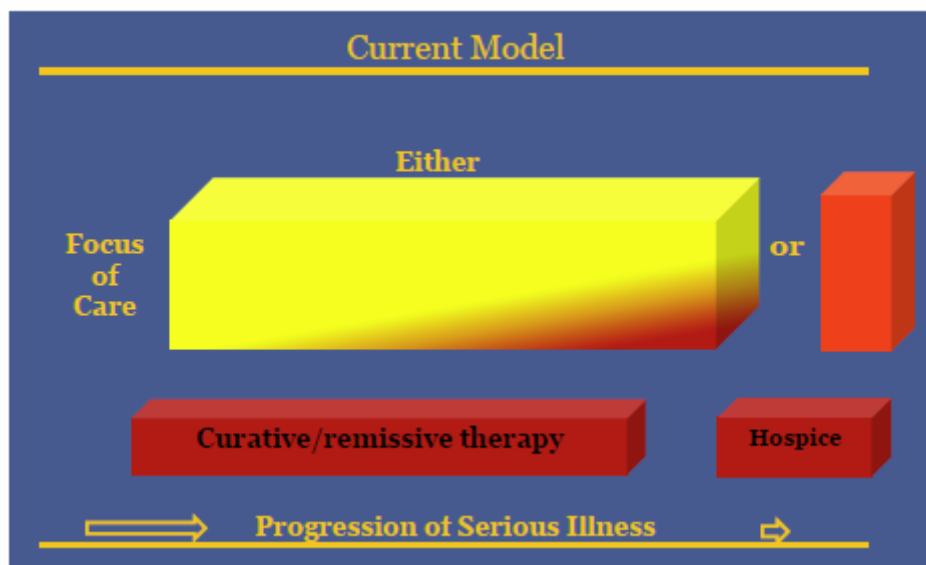
“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.¹”

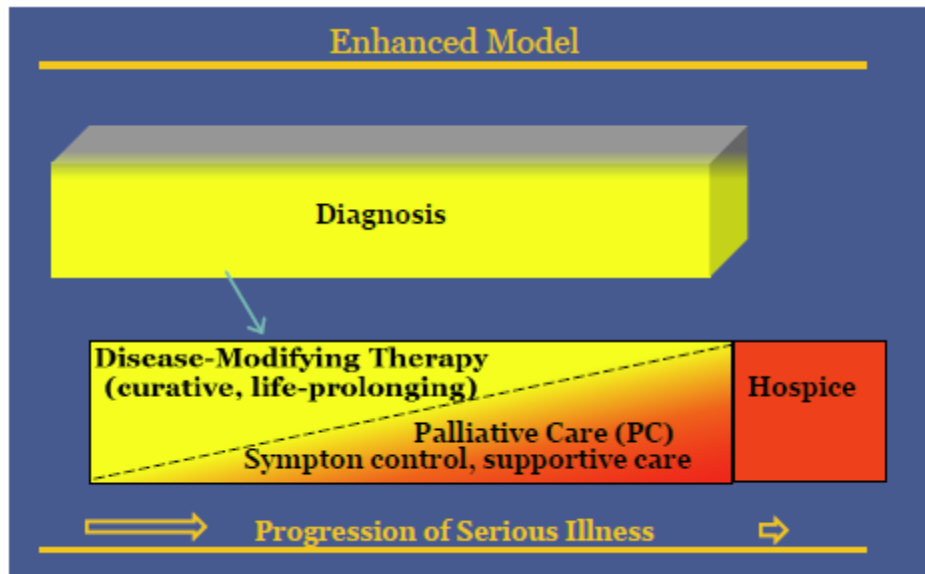
The timing of the provision of palliative services has been controversial. Often these services are available only at the end of life through hospice because of late referrals, inability to access palliative services, lack of palliative specialists or lack of reimbursement until the final stages of an illness. In fact, palliative care has a much broader scope, a role across the continuum of care, and potential to improve quality of life than just providing palliative care in hospice.

Palliative care and hospice care services are being reevaluated across the country, to change the paradigm so that palliative care will be provided throughout illness, instead of only at the end of life. Increasingly the health care provider community and policymakers are recognizing the need to provide services such as treatment of pain and symptom management to patients at the time they receive a potentially terminal diagnosis.

Figure 1 reflects the old definition, with a sharp demarcation between curative medicine and palliative care in the top portion of the figure. In the bottom portion of the figure there is a gradual seamless transition along the entire course of disease beginning with diagnosis and ending with the patients’ death.

Figure 1: Current and Enhanced Models for Delivery of Hospice and Palliative Care²





The word palliative has its origins in a Latin term for cloak (*pallium*). The meaning evolved to imply care that would reduce the severity of pain or 'cloak' it. The concept of palliative care and end of life care has evolved. Even with more research, the distinction between curative medicine and palliative care remains ambiguous, in part determined by each patient's unique circumstance and goals.

Purpose

This guide is intended to assist your community in its efforts to increase access to palliative care and hospice care and to improve the quality of palliative care and hospice care services available in your community or region.

Baseline Assessment of Palliative and End of Life Care Services for Washington, DC

Leaders in cancer care in the District of Columbia recognized that there were gaps in services and variation in the quality of palliative and end of life care. They commissioned a study to gather information to be used to improve care.

The District of Columbia Cancer Consortium (DCCC) is a coalition of organizations and agencies that convene to facilitate collaborative cancer control efforts for the city. DCCC, as part of its strategic grant making effort, issued a request for proposals in 2010 for a report on the state of palliative care in the District of Columbia. The Grant Group, LLC was awarded the grant and conducted a survey of eleven institutions providing palliative care. Three institutions provided both palliative and hospice care, one hospice care only and seven programs provided only palliative services. The Grant Group LLC staff approached program directors or senior management and conducted extensive interviews and prepared a report entitled "Report on Sources of Palliative/End of Life Care." This report contains an assessment of availability of services, quality of care, accreditation and training of personnel as well as funding sources. This report is available at www.thegrantgroup-llc.com.³

In developing the survey/interview tool, The Grant Group worked closely with a committee of advisors with local expertise in palliative care in the District of Columbia. The Grant Group conducted interviews with the advisory committee to capture their recommendations, assessment of the state of palliative care, perceived gaps in services and examples of exemplary programs. The Grant Group developed a survey instrument for the palliative care programs and approached institutions providing care to request interviews. (The survey questions are included in this report as Appendix A).

The report revealed a broad range of services being provided in a variety of settings including skilled nursing facilities, hospitals, and home delivery systems. The recipients of care were primarily those individuals who qualified for the Medicare/Medicaid Hospice Benefit. Exemplary programs were able to supplement this available source of funds with foundation grants and institutional funds to provide additional services not covered by the benefit (such as training of family member(s) providing care), or to provide services to individuals who did not qualify for those benefits (e.g., those under the age of 65 and those receiving active treatment).

Programs reported restrictive reimbursement requirements by third party insurers and inaccurate public and provider perceptions about hospice and the meaning of palliative care. Recommendations included a need for more awareness for the public and awareness and training for providers, improving access to palliative and end of life for District of Columbia residents. There was also recognition that additional resources were needed to bring services to patients' homes and to assist caregivers.

Exemplary programs and best and challenged practices were identified by use of electronic health records to track patient care across settings, home visiting models of palliative care as well as traditional hospice delivery systems.

Case Study: Assessing Palliative/End of Life Care in the District of Columbia

Best Practice Models

The New England Journal of Medicine published a randomized trial of palliative care for patients with metastatic non-small cell lung cancer.⁴

Figure 2: Clinical Trial of Effect of Palliative Care on Quality of Life and Longevity

Patients in the trial were randomized to receive palliative care combined with standard oncologic care or standard oncologic care alone. The results were significant for several reasons. Patients who received the combination of palliative care and standard care lived longer. Quality of life measures were improved in the group receiving palliative care, fewer patients in the palliative group received aggressive end of life care, consumed fewer health resources and as a result was less costly.

The Grant Group identified many promising practice models being implemented in the District of Columbia through the key informant interviews and the survey process. These models delivered care in traditional settings such as inpatient or home hospice or nontraditional settings such as primary care teams using home care models for the chronically ill. The models The Grant Group selected to highlight are innovative because they have transformed their palliative care delivery models from current traditional to enhanced. In each case they provide palliative care in a framework that provides a seamless continuum of care rather than a piecemeal approach with little communication or coordination between providers and settings.

Using the Medicare/Medicaid Hospice Benefit

In the United States the Medicare Hospice benefit is a primary source of financial support for hospice care. Many of these benefits are also provided through the Medicaid program and private insurers. If patients have Medicare Part A and their physician certifies that their life expectancy is six (6) months or fewer they are eligible for this benefit. In order to access these services, however, one has to be willing to forego curative treatment. The hospice benefit can reimburse for 95% of the cost of medication and for inpatient respite stays. In addition, a variety of other services improve the quality of life for patients that are also a part of this benefit. These include volunteers who can assist family members who are caring for someone at home, 24 hour on-call nurses for crises, an almost total absence of out of pocket costs related to the terminal illness, and bereavement services for up to one (1) year. (See Figure 3 below listing Medicare hospice benefits)

Figure 3: Medicare Hospice Benefits⁵

Medicare covers the following hospice services to care for terminal illness and related condition(s):

- Doctor services
- Nursing care
- Medical equipment (such as wheelchairs or walkers)
- Medical supplies (such as bandages and catheters)
- Drugs for symptom control or pain relief (small copayment may be needed)
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling for you and your family
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care (small copayment may be needed)
- Any other Medicare-covered services needed to manage pain and other symptoms related to terminal illness, as recommended by the hospice team
- Respite Care in a Medicare-approved facility (e.g. inpatient hospice facility, hospital or nursing home) if your usual caregiver needs a rest for up to 5 days on an occasional basis

One facility interviewed in the District of Columbia paired their skilled nursing facility hospice inpatient unit with a home visiting program to provide palliative care in a variety of settings. Patients who required inpatient services were housed in the inpatient hospice unit. Those patients who could remain at home received care from a team who coordinated home visits to assist family members with hospice care. The team assesses patients when they are admitted to assure the families have made specific arrangements for death (such as funeral arrangements) and to provide the emotional support. Families are counseled so that they are adequately prepared for and expecting the changes that may occur in their loved one as they near death. The transition between home and inpatient care was nearly seamless from the patient perspective due to careful care coordination by the team.

This program offers 24 hours, seven (7) days a week service. Every patient is assigned a primary case manager (RN) hospice nurse. They typically visit 1-2 times per week but more often if needed. After the office closes, the program has an on-call team and patients can call and be triaged by phone. There is an emergency medication box provided to the family to keep in the home called the 'comfort box' that contains drugs to manage pain, anxiety, and nausea. Family members can receive phone guidance from an on-call nurse in the use of medications from the comfort box. Most services in this program are funded using Medicare, Medicaid or private insurance hospice benefits. Some care was provided for patients who did not qualify for hospice benefits using charitable donations. The teams caring for patients included not only palliative trained nurses and physicians but also social workers, religious personnel, volunteers, and sometimes art therapists and other personnel.

Using Home Visiting Programs

Many patients diagnosed with a serious illness have mobility issues that can be effectively addressed with home visiting program models. Bringing the services to the patient can reduce the burden of transporting seriously ill family members for caregivers. Home care can also permit health care professionals, social worker, and volunteers to observe conditions in the home and provide needed assistance to caregivers and patients.

Although more research is needed, reviews of home-based care have been favorable when examining patient satisfaction and pain and symptom control of patients followed by interdisciplinary teams with palliative care training.⁶ A meta-analysis examining preventive nursing visits to community living older adults found significant reductions in mortality and nursing home admissions.

More than a decade ago a chronic care delivery model was developed in the District of Columbia and piloted by a major hospital for patients with two (2) or more chronic conditions. These frail patients began to receive most of their care through house calls by a team of primary care physicians supported by nursing staff. Initially the house calls were interspersed with clinic visits, but the clinic visits were eventually phased out and all care was provided in the home setting. The model expanded to care for patients in nursing homes and hospices as well. The home visits were well received by patients and their families in part because patients no longer had to travel to the clinic for care. The sponsoring hospital achieved reductions in utilization of emergency room care and hospitalization days for these patients and supplemented the cost of the program. This model has been incorporated into the Affordable Care Act through a Medicare Demonstration project called “Independence at Home.”⁷ Components of the model include:

- Focus on caring for frail elders in the community
- Patients having two (2) or more chronic conditions
- House calls
- Knowledge of community supports and referrals
- Social workers and nurse practitioners involvement
- Clinical and non-clinical services provided
- Expanded care to nursing homes, hospitals and hospice for continuity for patients initially seen in home environment

Hospital/Skilled Nursing Facility

One hospital based facility in the District of Columbia established a relationship with their skilled nursing facility to coordinate the care of patients discharged from the hospital. Patients could be monitored by the palliative team as they transitioned out of the hospital. Record systems were maintained that were continuous after hospital discharge and the palliative team was able to continue care when patients were readmitted. Private foundation funds were used to establish a caregiver training program to assist families in learning skills they could use to care for terminally ill loved ones at home.

Use of Electronic Systems

Electronic health records are nationally recognized as a tool to improve the consistent capture of information, patient safety, and efficiency and can provide a continuous history across care settings. This continuity is particularly important in palliative care and hospice care when patients may be seen in different settings and by different providers. However, home-based and ambulatory care settings are less likely to have and use electronic systems currently, and/or may not be connected to the broader health system in which the patient is served. This creates gaps in recordkeeping when patients transition from one setting to another. When patients are discharged to home or readmitted to a different care facility than the one that initiated palliative care, new records are sometimes created and old ones may not be updated with the change in the patient's status or location.

Creative uses of electronic systems can eliminate gaps in services and facilitate tracking of patients across care settings (e.g., transitions from hospital to hospice to home and back again). One home health care agency piloted a program for a local hospice organization to provide home visits to palliative care patients. A home visiting team including a physician, nurse, and social worker and nursing assistants were assigned to each patient. Team members made visits to the home depending upon which services were needed. A standard electronic encounter form was developed and loaded onto laptops that communicated with a central server. When a team member visited a patient and recorded data the server automatically generated an updated electronic health record recording in real time information about the patients' status, the encounter and any additional services needed.

Another hospital based palliative institution used their internal medical record system to generate a reminder that communicated with the palliative care program when any of their patients were discharged or readmitted. This allowed palliative program staff to make contact immediately to facilitate continuity of services during transitions from one care system to another.

Decreasing Fragmentation of Care

Staff in exemplary programs communicated regularly about patient care. Some described daily meetings each morning to discuss the day's patients, problems, stage of illness, and their disease processes. The staff felt they needed to monitor every patient every day to determine what needs had arisen, and how the family was coping with the process as well as any symptom management issues or psychosocial issues that may have arisen since the last discussion. The teams caring for patients included not only palliative trained nursing and physicians but also social workers, religious personnel, volunteers, and sometimes art therapists and other personnel.

Providing Culturally Competent Care

Many programs hired staff that were culturally diverse and spoke a variety of languages. Some language issues were resolved using telephone translation services. The desire to maintain a culturally diverse staff was an important part of the program's ability to provide culturally competent care. Culturally competent care was perceived as being more complex than simply having the ability to speak with people in their native languages.

Sensitivity to different cultural traditions surrounding the end of life is also an important component of care. There are differences in how and whether death can be discussed as well as differences in how the period immediately following death is managed. Exemplary programs were successful in eliciting this information from patients, respecting their wishes and their traditions and incorporating them into the care that was provided. This can include allowing nontraditional religious personnel to attend to individuals, and taking into account preferences in the length of time between death and burial. It can also include observing cultural differences in whether death and dying can be directly referenced in speech. For example in some Asian cultures, death is viewed as shameful for the dying patient and their family, so direct references to terminal illness may be offensive.

Improving Funding Streams

Programs that were able to structure their funding streams to provide stable funding generally reported higher quality of care delivered to their patients. Most programs relied upon hospice benefits from Medicare, Medicaid, or private payers, while many programs used additional funding sources. Private foundations (either internal to the palliative care institution or external) were a very common source of additional funding. Some palliative care institutions incorporated provision of palliative care into their missions. These institutions used internal funding for care as a necessary extension of that mission.

Availability of Training and Program Support

Well trained staff and adequate program support can improve the quality of palliative care. The Center to Advance of Palliative Care (CAPC) is one source of training and program support in conducting a palliative program. CAPC provides training programs for those who may be interested in starting a palliative care program or for personnel who are beginning their work in a program. Each training site offers specialized education for those implementing a specific model of palliative care. Mentoring is available for a year after participation in the training program. Training for startup programs is available as well as training for existing programs seeking to improve. Customized training is also available through CAPC.⁸ Additionally, training is offered by the Harvard Medical School Program in Palliative Care Education and Practice. Most programs in the District of Columbia had one (1) or more staff who had participated in a palliative care training program.⁹

In addition to general training for administrators and staff, health care providers can participate in palliative care training programs that provide certification for nurses and physicians. These include the End of Life Nursing Education Consortium (ELNEC), The National Board for Certification of Hospice and Palliative Nursing (NBCHPN), and the Hospice and Palliative Medicine Board (HPM). Many of the programs in the District of Columbia had staff that held certifications in palliative care. Those staff members were considered valuable additions to the palliative programs. Many programs wished more staff were trained and/or certified. The general difficulties programs expressed in finding and retaining staff compounded the problem of hiring certified staff.

Staff members were trained in how to provide palliative care to meet physical and emotional needs of terminally ill patients as well as the emotional needs of the caregivers. A program on 'breaking

bad news' helped train physicians during grand rounds and other settings in a hospital based palliative program.

Caregiver Training

Many programs cited caregiver training as an unmet need. Some programs were able to supplement their resources with foundation grants to fund programs to train caregivers. Exemplary programs used supplemental funding to provide formal training for family members in how to provide care. This included training in nutrition and hydration, and ways to manage "letting go." A quiet room with music therapy was also made available to family members by one program.

Policies

Physician Orders for Life-Sustaining Treatment forms (POLST) are a major advance in end-of-life care. When local policies permit their use, they enable patients' advance directives to be respected wherever they are cared for (home, hospital, or nursing facility). The forms typically contain information on the patients' wishes for cardiopulmonary resuscitation, use of antibiotics, nutrition and other medical interventions. The POLST is usually signed by a physician, but the information can be shared with other health professionals who may be caring for the patients. The POLST should accompany the patient so that their wishes can be easily accessed as they move from one care settings to another.¹⁰

The District of Columbia implemented the Emergency Medical Services Non-Resuscitation Procedures Act of 2000, in August of 2006, so that an individual with a life-limiting terminal illness has the right to experience a natural death at home or at other "out of the hospital" locations. A formal District of Columbia protocol allows physicians to write Do Not Resuscitate (DNR) orders for patients living in the District of Columbia. This legislation establishes the out of hospital DNR referred to as the "Comfort Care Order" (CCO). Implementation of the "Comfort Care Order" authorizes EMS personnel to withhold cardio pulmonary resuscitation (CPR) for District of Columbia residents who experience cardiac or respiratory arrest as the result of a specified medical or terminal condition. Without this legislation, EMS personnel are required to perform CPR on all patients experiencing cardiac or respiratory arrest as the DNR orders only covered care within the confines of a health care institution.

Barriers and Challenges

The Grant Group staff also interviewed programs in the District of Columbia that lacked strong institutional support and were underfunded or completely reliant on Medicare/Medicaid hospice benefits without the ability to supplement funding. Some programs were unable to track patients when they transitioned to home or another care setting. Palliative and end of life services were sometimes limited to one (1) care setting alone and did not follow the patient as he or she transitioned to home or other institutional settings. Staffing turnover and staffing shortages were other problems that some palliative programs were faced with.

Consistent with national averages, many hospice programs reported that they did not receive referrals of patients soon enough. They shared concerns that they could do a better job in meeting patient and family needs if patients came to them earlier in the course of their disease rather than in the last week or two (2) of life. Several programs that provided residential care for patients at the

end of life had a one (1) week mean length of stay. Many respondents felt that their colleagues were reluctant to refer patients to palliative care because it signaled their colleague's inability to successfully cure or treat a disease (admitting defeat), rather than changing the goals of care from curative to palliative. Those providers who referred patients late in the course of disease or not at all may view palliative care as giving up on their patients. When providers referred their patients to palliative care, information about those patients did not consistently flow back to the referring physician.

Medicare/Medicaid Hospice Benefit

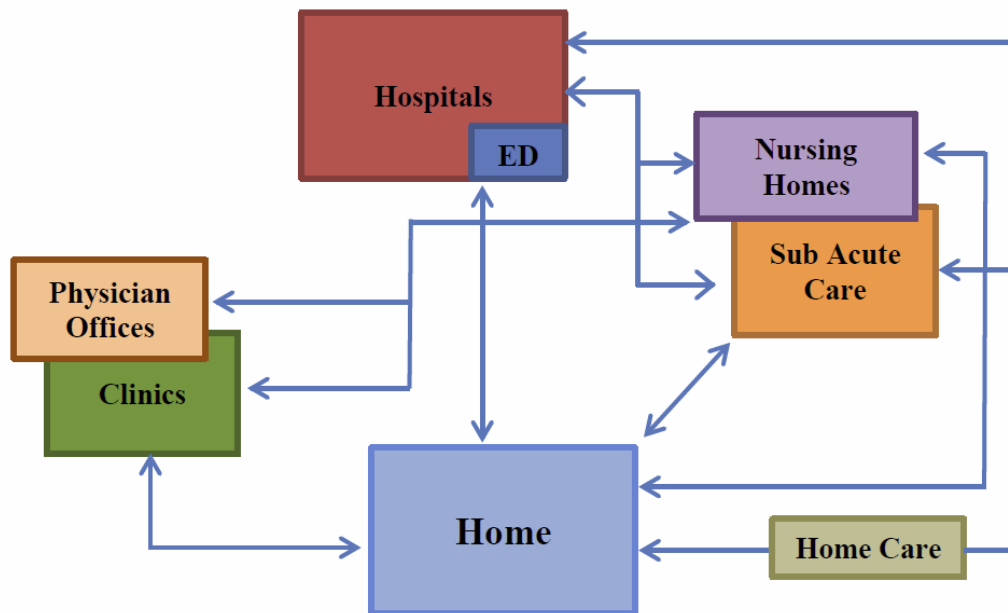
The biggest barrier to services cited by those interviewed was the inflexibility of the hospice benefit. It is the largest funding source for palliative care. Because access to hospice services is only available to those who are expected to die within six months it has contributed to the association of palliative care with the end of life. The hospice benefit defines care in a way that limits referrals by providers. Additionally, if patients are not willing to accept a limitation on potentially curative care, they may not be willing to accept hospice care. Lastly, restriction on the Medicare/Medicaid hospice benefit eligibility may limit the types of patients who can receive care, e.g. those who are not old enough for Medicare or Medicaid, have no private insurance or who make too much to receive Medicaid benefits.

Those patients who are not eligible for hospice benefits often are not offered palliative care because institutions have difficulty identifying a payment mechanism to reimburse institutions for palliative services outside of the hospice benefit. Some who are eligible for hospice benefits opt out or choose not to seek hospice care because they are unwilling to acknowledge they are nearing death or are unwilling to forego active treatment to qualify for the benefit.

Fragmentation of Care

Patients at the end of life often cycle rapidly between acute care, home and longer term care settings. It is difficult to track patients across these settings, let alone assure continuity of care. Family members are often overwhelmed when their ill loved one comes home with complex care needs such as pain management. An additional limitation of the Medicare/Medicaid hospice benefit is that when patients move from one care setting to another they may no longer qualify for the benefit and may lose their palliative care services. If patients opt to actively treat an acute condition and/or enter a hospital for active treatment they may have to be discharged from hospice eligibility while this treatment takes place.

Figure 4: Settings Where Palliative and Hospice Care Are Delivered⁶

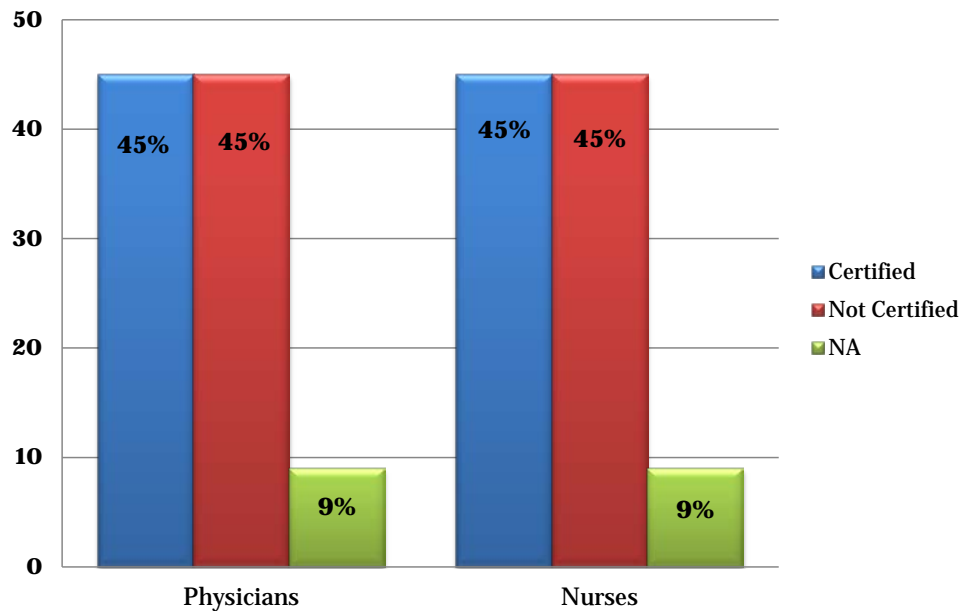


Lack of Trained Personnel

Many institutions expressed frustration at their inability to attract and retain staff trained and/or certified in palliative care. They often invest resources to train personnel only to see them leave their institutions for more lucrative employment. Less than half of the surveyed nursing and physician staff had received formal training in palliative care and were certified through either the National Board for Certification of Hospice and Palliative Nursing (NBCHPN) for nurses or the Hospice and Palliative Medicine Board (HPM) for physicians.

The survey of Palliative Care/End of Life Care in the District of Columbia revealed that roughly half of the programs reviewed had nurses who were certified as trained in palliative care by an accrediting body.

Figure 5: Physician and Nurse Certification through the Hospice and Palliative Medicine Board (HPM) or The National Board for Certification of Hospice and Palliative Nursing (NBCHPN)



Programs interviewed in District of Columbia reported equal rates of certification between nurses and physicians. Nine percent (9%) of the organizations did not have the information available.

Palliative care experts and those working in the cancer care community acknowledge that training of palliative specialists is important. There is growing recognition that referrals to palliative care might improve if those in primary care, oncology and other specialties that encounter patients earlier in the course of their disease received training as well.¹⁰

Programs such as “Educating Physicians in End of Life Care” (EPEC)¹¹ and offerings by MD Anderson Cancer Center and the Cleveland Clinic are all examples. If specialties such as internal medicine and/or general practice nursing provided exposure to palliative care during training, it could improve the availability of palliative care for all critically ill patients and increase referrals to and coordination with palliative care specialists. This would include specialized training in pain and symptom management and palliative care for medical students, residents, nursing students and faculty.¹⁰

Recruitment and retention of qualified staff was mentioned as a barrier by almost every palliative care and hospice care program we interviewed. Trained and/or palliative certified staff were scarce and highly valued. Because of reimbursement issues that varied from program to program, there was a wide variation in compensation that could be offered. This left some programs scrambling to retain staff that was easily lured away by higher compensation at other institutions. C-Change, a public private partnership working to improve cancer care and prevention, developed a list of competencies for health professionals who care for cancer patients through a consensus working group.

Figure 6: C-Change recommendations for competencies for all health professionals who treat cancer patients ¹²

C-Change recommends six (6) general palliative care competencies for health professionals treating cancer patients: (1) Define palliative and end of life care; (2) Assess that resources for palliative and end of life care and insurance coverage are consistent with current recommendations; (3) Refer patients to community palliative and end of life care and support resources; (4) Explain the role of hospice care; (5) Manage symptoms of the cancer patient; (6) Incorporate end of life comfort strategies for the dying cancer patient
www.cancercorecompetency.org

Perception of Palliative Care

Providers in the programs we surveyed reported that they were often reluctant to refer their patients and their patients were reluctant to seek palliative care because of their perceptions that this meant giving up on a cure. This was cited as a primary reason for patients being referred to hospice, for example, when they are very close to death, although they could benefit from palliative care much earlier in the course of their disease.

Transitions between Care Settings

Although there is a tremendous need for home based services, most of palliative and end of life care is still being delivered in hospital settings or in nursing facilities that receive the Medicare/Medicaid hospice benefits. Many patients report that they would prefer to be cared for at home at the end of their lives.

The barriers to home care are many. Family members sometimes feel ill equipped to care for dying family members and training is not a current reimbursable Medicare/Medicaid benefit under hospice.

Some residential care settings in the District of Columbia cared for patients who are very close to death with the average stay being close to one (1) week. Patients staying longer than six (6) months in a hospice funded facility ran the risk of losing their benefits or had to be transferred to other longer term facilities that are not necessarily focused on providing quality palliative care.

Geographic barriers can contribute to disparities in care. In the District of Columbia most of the major medical centers offering palliative programs were in the northern or western sections of the city. This overlapped with higher socioeconomic status areas of the city. Lower income, less well educated District of Columbia residents were geographically distant from the sections of the city where palliative care programs tended to be located.

Governance

Autonomy and/or lack of parent institutional support were cited by many facilities as barriers to providing quality palliative care to their patients. Facilities that were subsidiary units within a hospital or nursing facility often were a low priority for their parent institution and did not receive sufficient institutional resources to provide comprehensive services. For those institutions it was critical to have the support of the parent institution. This support could mean establishing policies that were friendly to the transfer of patients from one wing to another. That support could also be manifested by parent institutions that are subsidizing the cost of uncovered services.

Pediatric Palliative Care

There are special challenges in providing palliative to pediatric patients. Reimbursement may be limited to the health care provider. Home care services are very limited because they are generally not reimbursable and training for family members caring for children at home is almost nonexistent.

Best Practices

Pediatric palliative specialists in the District of Columbia recommended free standing palliative clinics that provide care outside of a hospital setting. Pediatric palliative specialists interviewed in the District of Columbia reported that once their patients were discharged from an acute care setting there was a gap in services leaving patients unable to get needed assistance with pain and symptom management that was more available for adult terminally ill patients. Pediatric palliative clinics could be a source of multidisciplinary care for patients who are not hospitalized to assist with pain and symptom management.

Care coordination and patient navigation were other gaps in service that were felt more acutely in the pediatric setting. Patient navigation services for pediatric patients can help families of terminally ill children cope with care transitions and care coordination. As with other patients, pediatric providers are often reluctant to acknowledge the severity of their patient's prognosis and the eminence of the end of life.

Barriers and Challenges

A survey of social workers, nurses, and physicians working in the Neonatal Intensive Care Unit and the Child Intensive Care Unit at a local children's hospital assessed use of palliative care services and attitudes towards those services. While nearly all providers surveyed "believed that end of life care was an important part of their job," many of the nurses and the physicians felt uncomfortable providing that care. Pediatric providers reported that part of the difficulty with providing pediatric palliative care is that specific training and certification for providers is limited.

For example, the American Academy of Pediatrics provides pediatric palliative care certification but the certifying examination is identical to the examination for adults. Pediatric palliative care providers at the survey institution also felt that their services were not fully utilized. At this institution there was no official palliative care service to admit patients and referrals were consequently limited and continuity of care and communication with primary care providers suffered.

Coordination of care is affected by limits on Medicaid reimbursement. Reimbursement for patient navigators to assist families of terminally ill children may require the use of external funding sources such as private donations. In assessing pediatric care it is important to examine care across all spectrums to determine the extent to which pediatric hospice care is available and what reimbursement mechanisms are available. One challenge to providing care for pediatric patients is the availability of home health services. Another challenge is the availability of trained pediatric palliative care specialists.

What Can Be Implemented in Other Communities

Some of the most promising elements of palliative care in the District of Columbia that can be implemented in other communities are:

- Using innovative reimbursement models to provide home visiting services such as CMS’s Independence at Home program that focuses on frail elderly patients with multiple conditions that is being implemented as part of the Affordable Care Act.⁷
- Leveraging electronic health records to track patient care across multiple settings to improve continuity, safety, and cost savings
- Supplementing palliative care by identifying resources to train family members to care for relatives
- Providing respite care for families of pediatric patients through hospital-based programs.

INDEPENDENCE AT HOME: Primary care physicians and nurse practitioners receive a financial bonus for visiting patients with several chronic conditions in their homes under a Centers for Medicare/and Medicaid Services (CMS) demonstration program.

Using the Medicare/Medicaid Hospice Benefit as a Platform for Palliative/Hospice Care

Patients who have a terminal diagnosis with a life expectancy of six (6) months or fewer who agree to forego curative treatment may be eligible to receive hospice services through the Medicare/Medicaid hospice benefit. Similar requirements and program benefits are reimbursable for enrollees in state Medicaid programs and through most private insurance plans.

The Medicare/Medicaid hospice benefit typically provides services for patients who are living at home but these services can also be provided on an inpatient basis, at a skilled nursing facility, or a palliative inpatient unit in a hospital. A definition of palliative care has been provided.⁶

“Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family... it can be delivered concurrently with life-prolonging care or as the main focus of care.”

Best Practice Models

Aetna piloted a nurse case management program for a selected group of enrolled members with advanced illnesses. Nurse managers contacted patients, physicians and family members by phone

to provide support with pain management, psychosocial needs and ensuring that the wishes patients expressed in their advanced directives were carried out. Evaluation of programs that offer telephonic case management by a specially trained nurses show significant reductions in hospital readmissions, physician office visits, hospital days, emergency visits, and higher rates of satisfaction in the telephonically monitored group.⁵

Some Aetna patients were given access to an enhanced hospice benefit that extended the time of eligibility for hospice benefits from six (6) months to 12 months and permitted patients to continue with curative treatment. More patients and family members expressed satisfaction with their care who participated in this model program as compared with patients receiving the standard hospice benefit. Additionally, the proportion of members electing the traditional hospice benefit improved compared with members who were not receiving these case management services. The total cost of care appeared to be reduced. Aetna has since expanded this program to all of their members who are eligible for care management services.¹³

Barriers and Challenges

The Medicare/Medicaid hospice benefit is generally restricted to those patients who agree to forego curative services. If an acute illness develops that needs to be treated, patients often have to be discharged from the hospice program, treated, and reenrolled after active treatment ceases. This restriction is a barrier and limits the number of patients who agree to participate in the program.

Hospital/Skilled Nursing Facility Based Palliative Care Programs

Patients who cannot be cared for at home may receive their palliative services in a hospital or a skilled nursing facility. These units often use the hospice benefits (whether through Medicare/Medicaid, Medicaid or private insurance) to cover their costs. Patient stays are typically short, and range from a few days to a few months. Hospitals often set aside a special in-patient unit or assign a team that consults and provides palliative services such as pain management. Similarly, skilled nursing facilities or long term care hospitals can designate areas that are devoted to caring for terminally ill patients.

Best Practices

The Ascension Health Care System adopted the National Consensus Projects Clinical Practice Guidelines for Quality Palliative care in an initiative that began in 2004. Volume, process and quality measures were adopted to integrate palliative and curative care. Pain and other symptom management improved within 48 hours of admission. The percentage of patients who completed advanced directives improved. Readmission rates dropped to one percent (1%) versus the national average of twenty percent (20%) and readmissions decreased significantly. Patients received palliative services earlier in their disease process and Ascension providers “began to understand that palliative care was not just for end of life patients.”¹⁴

These elements provide goals and measures that can be used to guide quality improvement efforts by communities who are interested in making improvements in their palliative programs.¹⁵

Figure 7: National Consensus Project agreed on the following key elements of palliative care.

- **Patient population:** The population served includes patients of all ages experiencing a debilitating chronic or life-threatening illness, condition, or injury.
- **Patient and family centered care:** The uniqueness of each patient and family is respected, and the patient and family constitute the unit of care. The family is defined by the patient or, in the e of minors or those without decision-making capacity, by their surrogates. In this context, family members may be related or unrelated to the patient; they are individuals who provide support and with whom the patient has a significant relationship. The care plan is determined by the goals and preferences of the patient and family, with support and guidance in decision-making from the healthcare team.
- **Timing of palliative care:** Palliative care ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues through cure or until death and into the family's bereavement period.
- **Comprehensive care:** Palliative care employs a multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social, and spiritual distress. Care providers should regularly assist patients and their families to understand changes in the patient's condition and the implications of these changes as they relate to ongoing and future care and goals of treatment. Palliative care requires the regular and formal clinical process of patient-appropriate assessment, diagnosis, planning, interventions, monitoring, and follow-up.
- **Interdisciplinary team:** Palliative care presupposes indications for, and provision of, interdisciplinary team evaluation and treatment in selected cases. The palliative-care team must be skilled in care of the patient population to be served. Palliative-care teams may be expanded to include a range of professionals based on the services needed. They include a core group of professionals from medicine, nursing and social work, and may include some combination of volunteer coordinators, bereavement coordinators, chaplains, psychologists, pharmacists, nursing assistants and home attendants, dietitians, speech and language pathologists, physical, occupational, art, play, music, and child-life therapists, case managers and trained volunteers
- **Attention to relief of suffering:** The primary goal of palliative care is to prevent and relieve the many and various burdens imposed by diseases and their treatments and consequent suffering, including pain and other symptom distress.

- **Communication skills:** Effective communication skills are requisite in palliative care. These include developmentally appropriate and effective sharing of information, active listening, determination of goals and preferences, assistance with medical decision-making, and effective communication with all individuals involved in the care of patients and their families.
- **Skill in care of the dying and the bereaved:** Palliative care specialist teams must be knowledgeable about prognostication, signs and symptoms of imminent death, and the associated care and support needs of patients and their families before and after the death, including age-specific physical and psychological syndromes, opportunities for growth, normal and aberrant grief, and bereavement processes.
- **Continuity of care across settings:** Palliative care is integral to all healthcare delivery system settings (hospital, emergency department, nursing home, home care, assisted living facilities, outpatient, and nontraditional environments, such as schools). The palliative care team collaborates with professional and informal caregivers in each of these settings to ensure coordination, communication, and continuity of palliative care across institutional and homecare settings. Proactive management to prevent crises and unnecessary transfer are important outcomes of palliative care.
- **Equitable access:** Palliative care teams should work toward equitable access to palliative care across all ages and patient populations, all diagnostic categories, all healthcare settings including rural communities, and regardless of race, ethnicity, sexual preference, or ability to pay.
- **Quality assessment and performance improvement:** Palliative care services should be committed to the pursuit of excellence and high quality of care. Determination of quality requires the development, implementation, and maintenance of an effective quality assessment and performance improvement program. This requires regular and systematic assessment and evaluation of the processes of care and measurement of outcomes using validated instruments for data collection.

Barriers and Challenges

For both hospitalized patients and for patients referred to palliative units within a skilled nursing facility, sometimes the referral occurs late in the course of the disease after the patient has been suffering from symptoms for a long time. “While expertise in palliation of pain and symptoms at the end of life has been developed, palliative care has not been well integrated with management of chronic diseases.”² Using criteria for referral that include an assessment of cognitive impairment, symptom distress, frailty and the demands for family support can help to guide health care practitioners who are trying to determine the appropriate time to initiate palliative care for elderly patients.⁶

Home Visiting Palliative/Advanced Illness Management/Home Based Primary Care

Palliative services are often delivered in the home setting, with family caregivers assuming responsibility for providing much of the care with assistance from visiting health professionals. Access to training can improve family member’s ability and comfort with providing care for their terminally ill loved ones. Palliative services can also be provided by health professional teams as a logical extension of home patients with multiple chronic conditions. When patients experience a decline in their condition, palliative services are phased into their regular care giving protocols. Twenty-two studies evaluating home-care palliative care teams/services were systematically reviewed and “revealed improved satisfaction and pain and symptom control when patients were followed by multi-professional teams of staff trained in palliative care compared to patients receiving conventional care.”⁶

Best Practices

The Veterans Administration, Johns Hopkins Hospital and Sutter Health have all implemented programs that manage the care of chronically ill individuals.¹⁴ The VA and Hopkins models deliver much of the primary care for these populations in a home setting. Health professional teams that include medicine, nursing, social work and sometimes pastoral counseling provide comprehensive management of patients who have two to four chronic conditions in their homes. Patients often report higher satisfaction with care delivered at home because it eliminates much of the burden they face traveling to clinics or hospitals for services.¹⁴

Advanced Illness Management (AIM), the Sutter model, provides a comprehensive planning process to assist patients with symptoms, medications and planning for the future. The focus of AIM is to shift the setting of care from the hospital to home and community.¹⁴ Home based programs have the potential to significantly reduce the number of hospitalizations, hospital days, and emergency room visits.

Barriers and Challenges

Hospital revenue can decrease if the parent institution for home visiting models receives reimbursement in a fee for service environment due to decreased utilization of emergency room and inpatient services decreases. An additional difficulty faced by institutions implementing this model of palliative care is hiring and retaining qualified staff.

Decreasing Fragmentation of Care

Palliative care and hospice services are implemented in many settings and by using a multitude of delivery systems. Often these settings and systems do not communicate with one another or follow patients as they transition from one setting to another. Payments systems that change as patients move from one system to another add another layer of complexity and contribute to fragmentation of care.

Best Practices

Electronic health records hold great potential for helping to decrease fragmentation by permitting the records that follow the patient be updated easily and accessed by a variety of providers in a variety of settings. These records can be used by palliative programs in hospitals to track patients as they transition to home or to a skilled nursing facility. They can also be used in home delivery care models to update records after a home visit takes place.

Some systems of care provide feedback to a hospital based palliative team so that when patients are readmitted the palliative service can resume care services. Some palliative programs coordinate care across many settings, following patients from in-patient stay to home or when they are admitted to a skilled nursing facility or to hospice. To reduce fragmentation of care it is necessary to create coordinated systems of care to ensure that providers of care can “...treat patients from the onset of a life-limiting illness until their death”.¹⁰

Challenges and Barriers

The use of electronic records requires a robust information technology system that has the potential to store and update records, while permitting portability and accessibility by the entire palliative care team. Care coordination systems have to be customized to fit the mix of providers, seamlessly flowing as patient’s transition from one setting to another. This requires agreements between providers and the institutions within which they function to allow for shared decision-making, shared data and improved continuity of care.

Training and Personnel

Increasing the percentage of personnel in palliative and hospice programs who are trained and/or certified can improve their quality of care. More health care professionals need to receive training in palliative care and hospice care. This is true for those who plan to specialize in providing this care and for those in other specialties.

Additionally caregivers can provide better care for terminally ill relatives in their homes if they are properly trained. Many caregivers undergo significant stress while caring for relatives and report needing more help in providing transportation or care than they receive.⁶ The stress of caregiving can lead to depressive symptoms in caregivers and interference with their lives.

Best Practices

The Center to Advance Palliative Care has conducted a training program for program managers in palliative end of life programs. The Leadership Training Center provides training with the

availability of follow up technical assistance and online programs. Training for start-up programs is offered through a module called Core which offers two (2) day small group sessions with a year-long mentoring service for adult or for pediatric programs. Programs in existence for one (1) or more years can take a Custom module offered for one (1) to two (2) days that is individualized to suit the program needs. The Custom module also offers mentoring. For established programs, Consult program brings experienced personnel to programs for site visits to assist with troubleshooting. Online training is also available.⁸

The End of Life Nursing Education Consortium (ELNEC) is a national education initiative to improve palliative. The project provides undergraduate and graduate nursing faculty, continuing education providers, and staff development educators with training by specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in palliative/end of life care. With this training, faculty and educators can teach this essential information to nursing students and practicing nurses. The project, which began in February 2000, was initially funded by a grant from The Robert Wood Johnson Foundation (RWJF). Additional funding has been received from the Open Society, the National Cancer Institute (NCI), Aetna Foundation, Archstone Foundation, the Milbank Foundation for Rehabilitation, California HealthCare Foundation, and the Department of Veteran Affairs (VA).

Some programs also provide training for non-palliative health care providers to assist them with developing skills in breaking bad news to patients, and encouraging earlier referral to palliative care.

Policies

Comfort care directives can be modeled after the Physician Orders for Life-Sustaining Treatment (POLST), first adopted in Washington State. POLST is a set of medical orders signed by a patient's physician, nurse practitioner or physician assistant to specify orders for life-sustaining treatment. It addresses the patient's wishes about when or if the patient wants to be resuscitated, to be transferred to a hospital, or to receive antibiotics, artificial hydration or nutrition.

Disparities in Access to and Quality of Palliative and Hospice Care

Aetna examined ethnic disparities in accessing the Medicare hospice benefit and found that its African American members were much less likely to choose this option. When Aetna's African American patients were offered the choice of receiving curative and palliative services they chose hospice at similar rates as white patients.¹³ A thorough examination of data in your community may reveal disparities in those receiving palliative and hospice care.

Cultural and attitudinal differences among patients experiencing serious life threatening illnesses can manifest in a variety of ways. In addition to the expected differences of language and cultures, there are differences in the role of religious personnel, family members, and beliefs around the meaning of suffering and whether suffering is acceptable.¹⁹ For example, during death as during life, some cultures (Orthodox Jews and Muslims) prohibit members of the opposite sex from touching the body. Many Jewish families prefer not to send cut flowers at the time of death and may observe a traditional mourning period immediately following death. There are a range of differences in terms of the interval before burial, the proper expression and duration of grief by

family members. In some cultures the orientation of the body and the color of the garments worn are of critical importance.¹⁶

Gender may affect how palliative care is delivered or who is referred for this care. Home care and the use of home visiting nurses may be influenced by the patient's gender.¹⁷ Studies have shown that symptom patterns differ according to both age and gender in patients with advanced cancer. Studies of male patients with advanced cancer have shown associations between pain, depression and anxiety that were not seen in female patients. This may increase the importance of pain management as a way of decreasing or better managing psychological symptoms in male patients.¹⁸

African-Americans and other ethnic/minority groups do not seek palliative and hospice care at the same rates as Caucasians. There are conflicting attitudes about death and dying in the African American community, with some believing that suffering and death are tests of character and to be endured rather than relieved. Only eight percent (8%) of those who use palliative and hospice care are African-American compared to eighty three (83%) of whites. More data is needed to understand the source of these differences.^{19, 20}

Geographic distribution of palliative care and hospice care services can contribute to disparities in care by limiting access. If palliative services are plentiful in one section of a community and scarce in another, residents who live in the underserved section may have limited access to palliative or hospice services. In the District of Columbia the Eastern and Southern sections of the city, where socioeconomic status is lower than in the West were geographically underserved. Outpatient services may be more available than inpatient services as inpatient care may not be available in close proximity to the homes of those seeking care. These geographic disparities place a burden not only on the patient, but on family members who must provide transportation or who want to visit loved ones who may be in residential settings far from home.

Perceptions of palliative and hospice care that vary across groups can contribute to disparities in access. "People in the community think that people are coming here (hospice) to die" is a common misperception that program staff in one District of Columbia hospice program frequently heard from community members. There is a perception that may be more common in one cultural group than another that their death may be hastened by going to hospice. People may fear that their loved ones will not be fed, or given life sustaining or prolonging medications. They may believe the pain medications will lead to chemical dependency. These perceptual barriers must be tackled head on before gaps in availability and acceptability of palliative and end of life services will begin to close.

The Implications of the Affordable Care Act

Implementation of the Affordable Care Act has the potential to greatly benefit the availability and quality of palliative care and hospice care services. Differences in state adoption of the Medicaid expansion benefit will cause the increased availability of palliative care services to vary depending upon the state in which you live. Expansion of private coverage will make palliative services more available to young people who can remain on their parents insurance until the age of 26 or for individuals previously uninsured who purchase private insurance through the exchange. The Essential Health Benefit, the minimum coverage available for insurance products sold through the

exchange, are likely to include a hospice benefit opening the door to hospice for many who were previously uninsured and whose income exceeded the limit to qualify for state Medicaid coverage.²¹

Medicaid Expansion

The effect of this expansion will be to make the Medicaid hospice benefit available to more individuals who were previously ineligible for Medicaid. As a result of the June 28, 2012 Supreme Court decision states now have the option of not implementing what had been a mandatory expansion of eligibility for state Medicaid programs. Prior to the decision, if states opted out of expansion they would have foregone the federal match for Medicaid. Now states can opt out of the expansion that would raise the threshold for eligibility to one hundred thirty-three percent (133%) of the federal poverty line. For example, a state that has used fifty percent (50%) of the federal poverty line as an eligibility threshold will have to raise its eligibility by eighty three percent (83%) by no later than January 1, 2014 if they adopt Medicaid expansion. For those states that implement the expansion which is scheduled to go into effect in 2014, the effect of this expansion will be to make the Medicaid hospice benefit available to more individuals who were previously ineligible for Medicaid.

Health Exchanges

All states are required to begin implementation of state exchanges or permit the federal government to operate an exchange within their borders by 2014. Some states are well on the way to building the necessary infrastructure to operate an exchange. Other states have made little or no preparation and may have to have their exchanges operated by the federal government. Whether federally or state operated, exchanges will allow the purchase of private health insurance for those who do not have the option of receiving health insurance through their employers and are ineligible for the expanded Medicaid benefit. The essential health benefit is the term used to describe the minimum set of benefits that any plan sold through the exchanges would have to cover. It is expected that hospice benefits will be included as part of the essential health benefit as does Medicaid, and most private insurance plans. This responsibility for defining essential health benefits was assigned to the Secretary of Health and Human Services when the Act was passed. Since that time the Secretary has indicated that state will have some flexibility in determining Essential Health Benefit for their exchanges.²¹

Individual Mandate

On June 28, 2012 the Supreme Court upheld the individual mandate under the Affordable Care Act requiring that US citizens purchase health insurance through the exchanges or through plans offered by their employers or pay a tax penalty. The mandate will help to ensure that many more individuals will have access to hospice benefits offered in private insurance plans.²¹

Independence at Home

The Affordable Care Act contains a provision called “Independence at Home” that provides financial bonuses for primary care physicians and nurse practitioners for home visits to patients with several chronic conditions and functional limitations under a Center for Medicare and Medicaid Services (CMS) demonstration program. If reductions in Medicare expenditures for these patients occur, savings can be shared between CMS and the provider. Practices selected for the

program must serve at least 200 Medicare fee for service beneficiaries and also coordinate patient care with other providers of health and social services.⁷

Medicare Part D

Gaps in coverage for the cost of medication have plagued the Medicare program since the passage of Medicare/Medicaid Part D. This gap in coverage affected Medicare/Medicaid beneficiaries enrolled in Part D plans who were required to pay one hundred percent (100%) of their medication costs after exceeding an initial coverage limit until they qualified for catastrophic coverage. This gap in coverage was referred to as the 'doughnut hole'. Passage of the Affordable Care Act closed the 'doughnut hole' by phasing in subsidies to assist with drug cost out of pocket expenses. In 2010 beneficiaries received a \$250 subsidy. Beginning in 2011 Part D enrollees received a fifty percent (50%) decrease in the cost of brand name medications. Additional subsidies for generic medications began in 2011 and will begin in 2013 for brand name medications.⁵

While these changes will have little effect on Medicare/Medicaid beneficiaries who are receiving the hospice benefit, those who are not receiving the hospice benefit, who are enrolled in Part D will be able to achieve some savings on the cost of medications once they exceed their coverage limits.²¹

Assessing Palliative and Hospice Care in Your Community to Make Quality Improvements

Step One: Quality of Palliative and Hospice Services

Strategies:

- Conduct Key Informant Interviews
- Review Data from Programs
- Evaluate Available Data

Conduct Key Informant Interviews: Conducting key informant interviews is an inexpensive way to collect information about access to and quality of programs. Potential key informants include leaders, managers or funders of palliative programs. They also can include patients or family members. These interviews can be done by phone and require a minimal investment of personnel time. Determine what questions you would like to answer that will inform the process of improving palliative and hospice care. Identify key individuals who are conducting palliative and hospice programs or who are critical opinion leaders in the field and arrange key informant interviews with them. Organize the information you receive into broad categories that reflect problem areas or gaps in services.

Review Existing Data from Programs: Collect existing data from palliative and hospice programs in your area. Make note of the programs that are unable to comply with data requests, as these may represent programs needing additional resources or serving specialized populations that have health disparities. The data that is collected during this assessment process can be invaluable in helping to highlight unmet needs and make a strong case for expansion. Examples of data that should be collected by exemplary programs include:

Operational metrics:

- Date of consult
- Cancer vs. non Cancer Diagnosis
- Origin of consult (e.g., ICU, ER)
- Date of Admission/Discharge
- Discharge Distribution (live discharges vs. inpatient deaths)
- Specific Diagnosis
- Referring physician/service
- Patient age
- Patient gender
- Patient race
- Disposition (discharged to skilled nursing facility, hospice or home)
- Hospital length of stay (time from admission to consult, consult to discharge and total length of stay)

Clinical metrics:

- Symptom control scores (e.g. pain, nausea, anxiety, depression, etc.)
- Psychological assessment scores

Consumer measures:

- Patient satisfaction
- Family satisfaction
- Physician satisfaction
- Staff satisfaction

Financial metrics:

- Daily pre and post hospitalization costs (costs of regular and diagnostic prior to and after hospitalization)
- Net loss/gain for inpatient deaths (change in percentage of inpatient deaths for patients receiving palliative care compared with patients not receiving palliative care)
- Case Mix Index (a measure of the variation across a group of patients based on condition severity and assignment of diagnostic codes).⁹

Evaluate Existing Data: Use preliminary evaluation as a way of identifying data gaps and unanswered questions. This step can help you identify what additional information you need to collect. It can also help you stratify programs based on their ability to report information on populations served and outcomes for those served. In addition to reviewing information that may already have been compiled about existing programs, you may want to collect additional data for review depending upon the availability of resources. Focus group sessions are an additional tool your community can use for gathering information.

Step Two: Review and Evaluation of Available Data on Quality of Palliative and Hospice Care

Once you have collected information on the palliative programs in your area, you will need to systematically examine aspects of the program.

Strategies:

- Program reach/demographic data
- Percentage of trained personnel
- Quality measures
- Funding streams
- Patient satisfaction
- Similarity to exemplary models

Who are programs reaching: Information on who programs are serving should include demographic data, age, sex, race, income, insurance type, geographic residence, diagnosis, stage of disease.

Percentage of trained personnel: Gather any available information about training that program managers have received and retention rates. Compile information about any palliative certifications that staff have. Has program management received technical assistance through a palliative care training program, such as the one offered by the Center to Advance Palliative Care? What percentage of the personnel who work in programs are trained and certified?

Quality measures: Some programs have set internal goals to evaluate their performance including measures such as time from referral to enrollment, average length of stay, or pain assessments. It is unlikely that all programs in your community will use the same criteria for evaluating their programs and/or services. Whatever measures they have can be folded into your overall assessment of the community's ability to deliver quality palliative and end of life care. National palliative care quality standards and preferred practices can be used for benchmarking by institutions, health care systems, and accrediting bodies. Standards can be found at sources such as the National Consensus Project, the World Health Organization, the Coalition to Transform Advanced Care (CTAC) and the Center to Advance Palliative Care (CAPC).

Funding streams: An examination of funding mechanisms may require going beyond the information that is collected through surveys or instruments. Some programs may be reluctant to share specific information about how care is funded. Traditional funding streams of Medicare, Medicaid and private insurance may not be sufficient to cover all care costs so it is important to identify additional sources of funding. Foundation funding is often used by institutions to externally fund gaps in care, but this type of funding is harder to obtain and is less sustainable. Identifying the care that is needed but is not provided due to reimbursement is an important task and a step towards improving quality of care.

Patient and family satisfaction: Do not overlook measures of patient and family satisfaction. This information may be harder to collect and less available across programs. Measures of patient and family satisfaction, however, are important in helping to assess the public's perception of the care they receive. This information can take the form of satisfaction surveys, letters of appreciation received by programs, or more formal survey data.

Similarity to exemplary models: Some programs are designed to mimic programs that have been successfully implemented and evaluated in other settings. In lieu of or in addition to a

formal evaluation process, assessing the similarities and differences to tried and true models can help to inform planning and strategizing for improvement of palliative care and hospice care in your community. To what extent have evidence based models been used to construct palliative programs in your community? Once you have identified models, it is important to create some criteria to help make a determination about which programs models are appropriate for your community.

Step Three: Determining if Disparities Exist

Strategies:

- Examination of demographics of patients served e.g., gender; ethnicity; age; income
- Map geographic distribution
- Conduct an environmental scan
- determine insurance status

Examine demographics: Depending upon the size, organization and administrative support available to a program, there may be databases that reflect the demographic profiles of current and/or past patients. Compile demographic information to create profiles of institutions and of the overall community.

Map geographic distribution: Most communities do a good job of serving a specific population or region. Mapping the locations of programs and the locations of the patients they serve can help you identify geographic areas and/or populations who are poorly served.

Conducting an Environmental Scan: If you have a funding source to assess the state of palliative and hospice care in your community or region, the community may want to commission an environmental scan. The scan can describe the status of palliative and hospice care for patients in that community. It can identify those environmental factors that have an impact on care and its delivery systems and identify those agencies and institutions providing care in that region, the barriers and facilitators encountered in providing that care. The scan would also outline opportunities and challenges for improving care in the region. Reviewing and synthesizing previously reported data to highlight factors relating to the delivery of palliative and hospice care can be a useful adjunct to the information collected from leaders in the field and from surveys of care providing institutions.

Insurance status: In much the same way that a map of geographic program locations helps to identify poorly served areas, identifying insurance status for patients and comparing that with any available statistics on the community as a whole is a worthwhile exercise. In many cases, patients who are in the final stages of their illness and who are eligible for the hospice benefit obtain services. But to be true to the definition of palliative care, services must be available to a broader range of patients and available much earlier in the course of disease.

Step Four: Analyze and Summarize Gaps in Palliative Care and Hospice Care

Strategies:

- Characterize populations underrepresented in palliative and hospice care programs
- Identify possible steps to reduce the disparities

- Review existing recommendations for quality improvement as they relate to disparities

Characterize underrepresented populations: Create a road map for action by characterizing the underrepresented populations, recognizing disparities in the provision of care and delineating the areas where quality improvements are needed. This strategic plan may not be able to be implemented all at once, but can help you and others in your community to identify short and long term priorities for action.

Identify steps to reduce disparities: It may be clear from the analysis of demographic, insurance and geographic profiles what is leading to underrepresentation of certain groups. Sometimes identifying the problem for program managers or key opinion leaders will motivate them to take small steps that can have a big impact on access to care.

Review quality recommendations related to disparities: Sometimes quality of care is not evenly distributed across all groups of patients. Patients may self-select programs based on how they view the care system and how appropriately their values, beliefs and concerns are reflected in the model of delivery. Quality improvement initiatives or staff recommendations for quality improvement may contain valuable recommendations that will assist with alleviating disparities.

Step Five: Developing Leadership to Make Recommendations to Improve Access and Quality

Strategies:

- Identify champions
- Create an agenda for improvements

Identify champions: Champions can help to lead the effort to improve services. A champion is a visionary leader who can see beyond their own institution to the broader community and who can convince policymakers or other key decision-makers to support the creation of a community framework for care. Champions are often found in the institutions that are providing the care or can be in the palliative and hospice care institutions themselves.

Create an agenda for improvements: Once leadership is in place and community leaders have assessed your community's current state of palliative care, develop a plan to address the need to improve quality of palliative and hospice care in your community. This plan needs to address the entire continuum of care (home, community and inpatient care settings) and to address palliative and hospice care needs for populations present in your community. This plan may not be able to be implemented all at once, but can help you and others in your community to identify short and long term priorities for action. The goal is to make palliative and hospice services available to all patients and available at all stages of disease.

Step Six: Convene Stakeholders for Action

Strategies:

- Engage policymakers by conducting briefings for administrative and/or legislative personnel
- Identify other community leaders
- Inform key stakeholders

- Engage media

Engage policymakers: Policymaker briefings can help to highlight gaps in services and needs for resources. Your community will need to develop a strategy targeting the most useful entities e.g., legislative committees or administrative agencies.

Identify other community leaders: Those working in programs or community advocates can assist with strategizing and implementing improvements in care in your community. People who now work in palliative programs or who worked in them in the past may be good advocates and allies as you plan for improvements in your community.

Inform key stakeholders: Stakeholder coalitions and champions should be engaged to assist with setting up these briefings. They can also mobilize their membership to make calls to critical decision-makers, prepare briefing documents and to serve as spokespersons.

Engage media: Strategic outreach to media is an effective way of raising public awareness of palliative and hospice care. Almost universally, there is a need to improve public perceptions about palliative care. The public and some providers equate palliative and hospice care with the end of life and this can make them reluctant to seek or refer for care. Strategies to change perceptions and make palliative and hospice care more acceptable will help more people receive quality services earlier in the course of their disease. An effective media strategy can achieve more than one goal. It can not only be an effective way to reach out to the public but can also augment efforts to engage policymakers and other decision-makers. This can help to counteract public fears exemplified by the death panel discussion that occurred during consideration of the Affordable Care Act.

Palliative and hospice care have many controversial issues spanning professional, economic, cultural and political boundaries. In some cases, oncologists and palliative medicine specialists disagree about care and communication strategies. Disagreements may exist about the definitions of care and competition for scarce resources in health care exists. Different cultures present a spectrum of views and vocabulary about cancer and death. These examples illustrate the complexity of this topic area, the thoughtful approach required to navigate the community, and the importance of a collaborative approach to untangle and align leaders towards common goals.

Summary

This guide provides a number of strategies, models and approaches to improve access to palliative and hospice care and the quality of that care in your local community. Changing the paradigm from old to new will be challenging. Doing so will require increasing the awareness of the need for services to be provided to a broader audience of patients and across all stages of disease. Policymakers, opinion leaders and even palliative and hospice program managers may be unaware of new evidence linking this new paradigm to improvements in quality of life and reductions in cost.

Using home visiting models that provide palliative care along with primary care, pairing inpatient services with home visiting to eliminate fragmentation, tracking patients across care settings, and expanding the access of palliative care support earlier in the course of disease are all examples of new approaches to providing care for patients with serious illness. It is our hope that you will examine the data supporting the effectiveness of these models to improve the quality of life for patients from the point of diagnosis, through treatment and survivorship, and at the end of life.

These models have been evaluated for their ability to improve coordination of care for palliative care and hospice care; cooperation among health care providers; professional education in palliative care for all health care providers; attention to quality measurement and outcomes; and family support. Many of these goals for quality improvement were reflected in the exemplary programs described above that were implemented in the District of Columbia. These palliative care and hospice programs were noteworthy in their ability to coordinate care, provide professional education in palliative care for health care provider peers, focus on quality, and provide family support programs. We hope this guide and the resources outlined in it will assist you as you work with others in your community or region to improve the quality of palliative care and hospice care in your community.

Resource List

Affordable Care Act Health Exchanges:

- <http://www.healthcare.gov/law/features/choices/exchanges/index.html>

Caregiver Training:

- <http://www.aasa.dshs.wa.gov/caregiving/training.htm>

Core Competency Programs:

- <http://www.cancercorecompetency.org/uploads/Pain%20Docs/C-Change%20Report%20University%20of%20Florida%20June%202010-%20F.pdf>

District of Columbia Comfort Care Policy

- <http://bioterrorism.doh.dc.gov/biot/cwp/view,a,1272,q,562635.asp>

Evidenced Based Palliative Care Models

- <http://advancedcarecoalition.org/?s=Aetna>

Independence at Home Demonstration:

- <http://innovations.cms.gov/initiatives/Independence-at-Home/index.html>
- <http://www.innovations.cms.gov/Files/fact-sheet/IAHfactsheet.pdf>
- <http://iahnow.com/>

Implementing Palliative Care:

- <http://www.capc.org/building-a-hospital-based-palliative-care-program/implementation/>

Medicare Hospice Benefits:

- <http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf>
- http://www.nhpc.org/files/public/communications/Outreach/The_Medicare_Hospice_Benefit.pdf

National Consensus Project Standards and Guidelines:

- <http://www.nationalconsensusproject.org/>
- <http://www.ncbi.nlm.nih.gov/pubmed/17531914>
- <http://www.ncbi.nlm.nih.gov/pubmed/20480209>

Providing Culturally Competent Care

- <http://www.dimensionsofculture.com/2011/09/the-role-of-religion-in-providing-culturally-responsive-care/>

Resources for Caregivers

- <http://www.terminalillness.co.uk/>
- <http://www.mayoclinic.com/health/cancer/CA00048>

The Grant Group, LLC. Report on Sources of Palliative/End of Life Care. The Grant Group, LLC 2010.

- <http://www.thegrantgroup-llc.com/>

World Health Organization Palliative Care:

- <http://www.who.int/cancer/palliative/en/>

End Notes

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APPENDIX



Appendix A

District of Columbia Cancer Consortium Palliative Care and EOL Care Strategic Planning Tool

This strategic planning tool was developed by The Grant Group to assist the District of Columbia Cancer Consortium in its' effort to assess palliative/end of life care in the District of Columbia and to plan for improvements in services. This tool is being shared to assist other communities engaging in similar assessment and planning efforts. In reviewing the tool we identified additional questions that may be useful for others who may wish to adapt this instrument for their own use. These questions were not used in the District of Columbia assessment but have been added below for you to consider as you create your own assessment tools. To maintain the integrity of the instrument and guide you about placement, these questions are included in the appropriate section, but bolded to set them apart from the original questions.

1. Organizational information

- A. Name
- B. Address
- C. Year Program Began
- D. Contact Person Surveyed
- E. Role of Contact Person in Organization

2. Staffing and Scope

- A. What number and type of staff are solely dedicated to providing palliative care?
- B. What number and type of staff spend part of their time providing palliative care?
- C. Are palliative services provided by consultants?
- D. Do you provide palliative care for children?
- E. What training are staff members required to have?
- F. What certifications do staff members who provide palliative care have?

3. Continuing education

- A. Do you conduct continued education for staff?
- B. If yes, is it a requirement?
- C. If not, is it contracted out and to whom?

- D. What is the continuing education/training schedule?
- E. What is the length of continuing education/training?
- F. What topics are covered?
- G. What incentives do staff members receive for participating in continuing education/training?
- H. Are materials available in hard copy or electronic form for participants
- I. May we receive copies of the materials?
- J. Are there certifications required for your staff to be able to provide palliative care?
- K. Are there measures of competency as well as participation?
- L. Is anyone on staff board certified by the Hospice and Palliative Medicine Board (HPM)?
- M. Are there plans to obtain board certification?
- N. Is anyone on staff certified by the National Board for Certification of Hospice and Palliative Nursing (NBCHPN)?
- O. Are there plans to obtain board certification?
- P. Are there ongoing continuing educations or training activities required for your palliative care staff?
- Q. Do you provide wellness or debriefing training for palliative care staff
- R. Are there social workers providing palliative care at your institution?
- S. Are there mental health professionals providing palliative care at your institution?
- T. Are there clergy or faith community members providing palliative care?

4. Capacity

- A. Describe the type of services family and patients receiving? Consultation service; outpatient palliative care; an inpatient palliative care geographic unit; a swing unit with palliative care beds; hospice care; palliative caregiver services?
- B. Approximately how many patients were admitted for palliative care last year?
- C. How many patients were admitted for palliative care this year?
- D. How many patients received consultation for palliative care last year?
- E. How many patients received consultations for palliative care this year?
- F. Is palliative consultation available 24 hours per day?
- G. How many patients/families received outpatient palliative services this year? Last year?
- H. What non-identifying information can you share with us about those families and patients? For example, age, gender, ethnicity, source (community, skilled nursing facility, ER, physician referral)
- I. What percentage of patients admitted for palliative care were cancer patients?
- J. What percentage of patients receiving consultations for palliative care were cancer patients?
- K. What percentage of the patients admitted for palliative care are diagnosed with chronic diseases (non-cancer)?
- L. What percent of the patients receiving consultations for palliative care are diagnosed with chronic diseases (non-cancer)?
- M. How many family caregivers is the program currently serving?
- N. What services are you providing for family caregivers?
- O. How do you collect information about the families and patients you serve?

5. Program Outcomes

- A. What are the outcomes and metrics the program tracks?
 - B. What national standards are utilized in structuring your approach to measuring outcomes?
 - C. Do you track the number of patients whose pain was reduced or alleviated?
 - D. Do you track the number of patients who finalized Advanced Directives as a result of the program?
 - E. Do you track the number of patients who were assisted with difficulty breathing?
 - F. Who is responsible in your organization for tracking?
 - G. Who is responsible for managing the tracking data?
 - H. Are metrics tracked on a continuous basis? If so, which ones?
 - I. Are metrics tracked on an intermittent basis? If so, which ones?
 - J. What continuity of care provisions do you have for palliative patients e.g. protocols for transfer of patients from your facility to another to ensure communication?
 - K. What quality improvement activities do you have for your palliative care services?
6. Funding sources
- A. Do you receive funding from private donors or foundations?
 - B. Are your palliative services reimbursable by private insurers?
 - C. Are your palliative services reimbursable through Medicaid?
 - D. Are your services directly reimbursable through Medicare? If not, do you have a contractual arrangement with a hospice agency that reimburses you for palliative care?
 - E. What are the percentages of payers e.g. 25% Medicaid, 30% private pay etc.?
 - F. Do you consider your funding sources to be stable?
 - G. If yes, for how long have your funding sources been stable?
7. Availability
- A. How do patients request or access service?
 - B. What is the typical interval between a request and intake?
 - C. What is the typical interval between intake and regular services?
 - D. Are there criteria that would determine that a patient is not eligible to receive your services?
8. Internal Integration
- A. If you have a mix of providers (some in house, some contractual) can you describe the mix?
 - B. Are there differences in the patients who are seen by the different kinds of providers?
 - C. Are there differences in the services provided by the different providers?
 - D. How would you describe your institution's commitment to palliative care?
 - E. What percentage of the care you offer is palliative?
 - F. Are these services tracked differently than other health care services?
9. Education and support to families and other unlicensed caregivers
- A. Is there a fee for services?
 - B. What triggers the provision of these services to the patient and family?
 - C. When are the services provided?
 - D. Who provides the education services?
 - E. Who provides the support services?

10. Culture

- A. Is there ever an attempt made to select a service provider who is of the same cultural background?
- B. Is information about the patients' cultural background collected at time of intake?
- C. Do you have service providers of different cultural backgrounds?
- D. Is information about the patients religious preferences collected at time of intake?
- E. Is there ever an attempt made to refer patients for religious counseling?
- F. Is the staff culturally competent?
- G. What is the ability to interact with different institutions providing palliative care for your patients?
- H. How are referrals passed along?
- I. What communication systems exist between your institution and the other institutions where your patients are cared for?

11. Special Services

- A. Describe the availability of special services, such as interpreters and material in languages other than English.
- B. Are service providers available who speak a language other than English? If so which languages?
- C. Do you market services in languages other than English? If so, which language.

12. Advance Directives

- A. Do you ask if a patient has an advance directive at time of intake? If no, at some other time?\
- B. Do you ask patients if they have a do not resuscitate order at time of intake? If no, at some other time?
- C. Is information about advance directives recorded or tracked?
- D. Who is responsible recording or tracking the information?
- E. If patients do not have an advance directive are they offered one?
- F. How is the information tracked or recorded?

13. Promotion – [For hospitals]

- A. How is the program promoted internally?
- B. How is the program promoted externally?
- C. Are there incentives for providers to offer palliative care to patients at your facility?
- D. If yes, what kind of incentives?
- E. Are there disincentives for providers to offer palliative care to patients at your facility?
- F. If yes, what kind of disincentives?
- G. Is palliative care reimbursed in the same way as other care?
- H. Are non-reimbursable palliative care services provided?
- I. If so, how are those costs covered?

14. Barriers and Challenges

- A. What are the barriers and challenges facing the palliative and EOL care program?
- B. What are the barriers and challenges faced by the palliative and EOL team?

- C. How has the program addressed the barriers or challenges?
15. Community, state or national (informational/technical assistance/collaboration) resources
- A. What guidelines influence provision of palliative care services at your institution?
 - B. Are there resource materials from outside organizations used to provide palliative care at your institution? If so, what?
 - C. Have you consulted with an outside agency or technical resource in the design of your palliative care program?
 - D. Do you regularly use an outside resource in the provision of palliative care at your institution?
16. Future Plans
- A. What are the organization's plans for expanding the program?
 - B. What is the timeline for that expansion?
17. Community Support
- A. What organizational support could the palliative and EOL care program at your institution use?
 - B. From what organization/agency would you seek that support?
18. Policy or legislation
- A. Is there any policy or legislation that would benefit residents in DC receiving palliative and EOL care?
 - B. Is there any policy or legislation that would benefit your institutions efforts to provide palliative and EOL care to DC residents.
 - C. Are you aware of plans to change the DC Medicaid rules to permit palliative care for children to be reimbursed under Medicaid?
 - D. Would this affect your institutions work in palliative care?

Appendix B

IMPROVING DELIVERY SYSTEMS FOR PALLIATIVE AND HOSPICE PROGRAMS*

*See Resource listing for more information about model programs

BEST PRACTICES					
Medicare Hospice	Aetna Enhanced Hospice Care Management Plan	Hospital/Skilled Nursing Facility Based Palliative Programs	Home Visiting /Advanced Illness Management/Home Based Primary Care	Decreasing Fragmentation	Training/Personnel
<ul style="list-style-type: none"> • Team including variety of staff e.g., social work, volunteers, religious personnel, art therapists • No out of pocket expenses for families • Smooth transitions (home to inpatient care) • Regular communication across the team to manage care • Tailoring services to patient/family belief systems • 24 hour/seven(7) day a week availability of palliative specialists • Ability to assess and manage psychiatric disorders like delirium 	<ul style="list-style-type: none"> • Hospice requirements allow care within 12 months of terminal diagnosis (versus six (6) months) • Both curative and palliative care permitted to be provided to patients • Higher hospice referral rates • Trained nurse care managers conducted telephone consultations with patients, physicians and families • Assistance provided with pain, adherence to advanced directives and psychosocial needs 	<ul style="list-style-type: none"> • Provision of palliative care services by a specialized team operating within a hospital or skilled nursing facility • Care management shared by referring physician and palliative professionals • Pairing inpatient hospice with home visiting program so that patients can transition seamlessly from one to the other 	<ul style="list-style-type: none"> • Integrated palliative and chronic care models • Tailored home visits from team of professionals to meet patient and family caregiver needs • Longitudinal rather than episodic care focus • Comprehensive and patient centered care addressing physical, social and behavioral conditions • Concurrent electronic record documentation with each visit • Emergency medication available in the home • 24 hour on call assistance available to families <p>Ability to schedule home visits with short lead time</p>	<ul style="list-style-type: none"> • Electronic record follows the patient across care settings • Real-time EMR interface • Providing palliative care in the home environment to the chronically ill • Managing transitions for homebound patients to other settings 	<ul style="list-style-type: none"> • Basic training for family caregivers • Training of primary care and other health professionals in palliative care at parent institution • Specialty palliative care certification for physicians and nurses and social workers • National training resources: Center to Advance Palliative Care Program Training and ELNEC Training Program • Residency palliative grand rounds this was not discussed in the paper

CHALLENGES/BARRIERS

Medicare Hospice	Aetna Enhanced Hospice Care Management Plan	Hospital/Skilled Nursing Facility Based Palliative Programs	Home Visiting /Advanced Illness Management/Home Based Primary Care	Decreasing Fragmentation	Training/Personnel
<ul style="list-style-type: none"> • Access to pain specialists • Ineligibility of some patients for Medicare hospice benefit e.g., life expectancy; < 65 with no private insurance. • Limit of six (6) months eligibility • Reluctance of physicians to refer patients • Perception that palliative care means giving up • Inability to follow patients after referrals to palliative care are made • Lack of communication between referring physician and palliative providers • Uncovered services such as training for caregivers 	<ul style="list-style-type: none"> • Reduced racial disparities among those receiving hospice care • Aetna permits only its private payers to use this model • Waiver of Medicare requirement of six (6) month terminal diagnosis would be required for eligibility 	<ul style="list-style-type: none"> • Fragmentation of care with referring physicians • Limitation of six (6) months length of stay requirements for patients with unpredictable course of disease 	<ul style="list-style-type: none"> • Both curative and palliative treatment permitted • Reduction of inpatient days Reduction of total cost of care reduces revenue for the hospital • Earlier and more frequent transitions to hospice care as patients illnesses progress • More intensive use of personnel resources to deliver care in the home • Increased need for communication across the team about patient conditions • Difficulty hiring and retaining professional staff 	<ul style="list-style-type: none"> • Lack of coordination across multiple institutions providing palliative care • Lack of EMR system or integration across care settings 	<ul style="list-style-type: none"> • Workforce shortage • Few certified staff • Costly palliative care training • Lack of incentives for staff to obtain certification • Low retention rates

CHALLENGES/BARRIERS

Medicare Hospice	Aetna Enhanced Hospice Care Management Plan	Hospital/Skilled Nursing Facility Based Palliative Programs	Home Visiting /Advanced Illness Management/Home Based Primary Care	Decreasing Fragmentation	Training/Personnel
<ul style="list-style-type: none"> • Uncertain prognoses that do not permit providers to predict death within six (6) months • Difficulty determining course disease will take • Multiple and rapid transitions between care settings e.g., home, skilled nursing facility, ER, inpatient hospital 		<ul style="list-style-type: none"> • Limited reimbursement • Hospital parent institutions may receive less reimbursement when hospitalizations and ER visits decrease 			