Delivering Palliative Care in the Home

Drs. Martha Twaddle and Elizabeth McCormick review the current landscape and what’s involved in delivering home-based palliative care — from the different models now in use and the specific components of a palliative care home visit to the role and burdens of caregiving.
**Palliative Care Innovators**

For over a decade, the American Hospital Association has presented the prestigious Circle of Life Award® to honor innovation in palliative and end-of-life care. Here’s a closer look at this year’s honorees, including longtime NHPCO member, Lehigh Valley Health Network.

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**Ethical Challenges for Hospice Managers**

“Ethics for Hospice Managers” is one of the most popular modules offered in NHPCO’s Hospice Manager Development Program. As the program celebrates its 10-year anniversary, Dr. Paul Longenecker, who has taught the module since its inception, looks back on the ethical issues raised by module participants, and discusses how the evolving world of health care and hospice has affected the ethical aspects of practice.

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**A New Way to Access NHPCO Expertise**

A new service is being unveiled to help you tap into the expertise of NHPCO’s staff and consultants on a host of operational, regulatory and strategic issues. This article provides details.

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**Plus, This Year’s Volunteer Honorees!**

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**News From National Hospice Foundation**

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A New High

The hospice community could not ask for a better advocate than ER physician, Dr. Ziad Obermeyer, who is the lead author of an important new study in the *Journal of the American Medical Association*.

The study provides data to support what we see every day, namely that cancer patients under hospice care are better able to live comfortably and more fully at the end of their lives. Barry Kahn, the husband of a patient who elected hospice care, stated this beautifully in the *JAMA Network* video about the study.

But the big news was the cost savings. The 18,165 Medicare patients who received hospice care, vs the matched control patients who did not receive hospice care, had lower rates of hospitalization (42% vs 65%), intensive care admissions (15% vs 36%), and invasive procedures (27% vs 51%), in addition to lower total expenditures during the last year of their lives. The overall savings amounted to about $9,000 per hospice patient — a new high.

That said, as former NHPCO board member, Joan Teno MD, MS, and her colleague, Pedro Gozalo, PhD, point out in their *JAMA* editorial on this study, it is the quality of the care, not the cost, which should drive health care policy. They also rightfully argue that the necessary quality measures are still not in place to ensure that all dying patients receive quality care.

Although more work is clearly needed, Congress has now taken a very significant step with the passage of the IMPACT Act, signed into law by President Obama on October 6, 2014.

Provisions in this new law should result in greater oversight and increased transparency within the entire hospice community, including mandated surveys of Medicare-certified hospice providers every three years (at a minimum) over the next 10 years.

As many of you know, NHPCO leadership has long supported the need for more frequent surveys. This will help ensure that every Medicare-certified healthcare organization offering hospice care provides the appropriate level and scope of care at the right time in the patient’s life.

While voluntary, NHPCO offers patient-centered measures and family evaluation survey tools to help hospices assess and improve upon the care they are providing. If you are not already utilizing these resources, please see www.nhpco.org/performance-measures.
Delivering Palliative Care in the Home

By Martha L. Twaddle, MD, FACP, FAAHPM, and Elizabeth McCormick, MD
This past September, the Institute of Medicine released the consensus report, *Dying in America*, with findings and recommendations from an expert panel of healthcare professionals on improving quality and honoring individual preferences near the end of life.

Many of the findings will come as no surprise to NHPCO members, namely that palliative care is associated with higher quality of life as well as a reduction in health care costs due to lessening use of acute care services. But the report also calls for making changes in payment systems to incentivize the provision of comprehensive palliative care, among other noteworthy recommendations.

As greater attention is placed on the value of palliative care in helping to fix a fragmented health system, it’s more prudent than ever to explore the viability of providing this care in your own community.

Toward this end, Drs. Martha Twaddle and Elizabeth McCormick review the current landscape and what’s involved in delivering home-based palliative care. You’ll learn more about the different models now in use, the specific components of a palliative care home visit, the role and burdens of caregiving, and where coverage for these services now stands.

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**The Patients Most in Need**

Patients who benefit from home-based palliative care are typically those with advanced complex illnesses or life-limiting diagnoses and a high risk of morbidity and mortality. These individuals most often do not have a predictable prognosis and, thus, are not eligible for or interested in electing formal hospice services.

These patients are also among an increasing number of elderly and frail individuals who are homebound and suffering from significant symptoms associated with their diseases, particularly pain and depression. What’s more, over 50 percent of these patients prefer to be cared for in the home setting, specifically expressing this preference when asked about end-of-life care.

**“Homebound” Defined**

While palliative care is ideal for patients who are “homebound,” there are no universal criteria to define what makes a patient homebound. In the United States, reasonable criteria have been set by the Medicare homebound rule. These apply to patients with a serious illness and those who have experienced a serious injury.

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In order to qualify as homebound, such persons need the aid of supportive devices (e.g., crutch, cane, wheelchair, walker, or special transportation), OR require the assistance of another person in order to leave their place of residence, OR have a condition that renders leaving their home medically contraindicated.

In addition, patients should be unable to leave the home normally, such that attempts to do so would require a considerable and taxing effort.

It is important to note that at least in the U.S., patients receiving home-based palliative care are not required to meet the definition of being homebound as it applies to home health, particularly if the clinician determines it is medically necessary to see a patient in the home setting to optimize their assessment and treatment plan. However, documentation of the need for home-based care is required for medical coverage.

**Current Models**

In the U.S., there are several models for the provision of home-based palliative care services. Many factors determine which models can be available in a patient’s community, including constraints of the local health system; local coverage for services (including insurance and other payers); and financial resources of patients in the catchment area.

Home-based palliative care services may be offered as part of a geriatrics or primary care practice with expertise in palliative care (primary and palliative care), or through home care (home health-based), hospice agencies, or a hospital-based palliative care program. These are discussed below.

**Home-based Primary and Palliative Care Model**

Home-based primary and palliative care programs integrate palliative care into comprehensive primary care provided by an interdisciplinary team.

Home-based primary and palliative care programs may be based in private primary care practices, academic medical centers, community-based non-profit organizations, or within hospital-based health systems (e.g., Veterans Affairs Medical Center).

These teams are most often led by a physician or advance practice nurse, and can include nurses, clinical pharmacists, social workers, psychologists, and physical therapists. Team members most often have added training and expertise in palliative care to allow them to extend their services to the home.

Home-based primary and palliative care programs provide home visits during business hours and most provide 24-hour and weekend phone availability.

In addition, many programs are able to deliver medications to the home, much like hospice, and also provide longitudinal primary care, urgent care, and transitional care.

Patients enrolled in these programs are primarily homebound patients with multiple chronic medical conditions, high symptom burden, and/or complex care coordination needs. For these patients, the bundling of primary care with specialty-level palliative care can be particularly advantageous because it affords the integration of palliative care principles into longitudinal health care.
relationships and can reduce the symptom burdens of patients\textsuperscript{11}.

Access to specialty palliative care support has been demonstrated to improve quality of life for patients and their caregivers, lower the burden of home care for the caregiver, improve symptom management, and decrease unnecessary hospital and emergency room utilization\textsuperscript{1,12}.

Although data are limited, they appear to support the use of these programs. For example, in one observational study, 140 patients enrolled in a home-based palliative and primary care program were followed using telephone-based surveys to assess symptom burden. Patients reported significant reductions in symptoms (including pain, anxiety, depression, fatigue, and loss of appetite) as early as three weeks following enrollment, which were maintained at 12 weeks\textsuperscript{13}.

**Home Health-based Model**

Two types of services can be provided in the home:

**Home Health Care**

This is frequently used as a post-acute care delivery provider, although it is also available for patients without a preceding hospitalization if their provider has determined skilled nursing need is necessary, such as:

- Frequent monitoring of blood pressure, fluid status, or blood glucose
- More rigorous assessment of symptoms, including pain, dyspnea, and constipation
- Patient education around therapy (e.g., home glucose monitoring and insulin self-administration)
- Assessment of medication adherence.

The main mission of home health care is rehabilitation. As a result, most U.S. agencies do not offer 24/7 support or emergent home visits, and usually do not deliver medications to the home. Patients are eligible for home health under Medicare Part A when they require intermittent skilled nursing and/or physical, occupational, or speech therapy\textsuperscript{6}.

**Palliative Home Health Care**

Sometimes referred to as ‘home health-based palliative care,’ this care is typically provided by an interdisciplinary team like home-based primary and palliative care programs. However,
palliative home health care is not reimbursed as a Medicare Part A benefit.

Home health services can combine rehabilitation with the competencies of palliative care (to relieve suffering, alleviate distressing symptoms, and facilitate discussion around realistic goals of care, and documentation of advance care planning). Access to professional support has been demonstrated to improve quality of life for patients in palliative care and their caregivers, lower the burden of home care for the caregiver, improve symptom management, and decrease unnecessary hospital and emergency room utilization. That said, patients with advanced and/or end-stage disease may derive limited benefits from home health services because care is often time limited to a particular episode for which skilled needs have been defined. As a result, once the objective of care is met, a patient is usually discharged without assistance for ongoing care management. This can be a particularly vulnerable time for patients with complex illnesses. In our experience, it is not unusual for the organization of care to deteriorate after home health care has been discontinued, which increases the stress for the caregiver.

**Hospice Model and Bridge Programs**

Hospice is the most intensive, refined form of home-based palliative care for patients whose life expectancy is typically defined in months and who are no longer benefiting from disease-directed interventions. In the U.S., many hospice programs have established home-based palliative care “bridge” programs for patients who do not choose to elect the hospice benefit or do not meet hospice eligibility criteria at the time of referral. The services provided by bridge programs vary widely and they are not regulated or standardized. Some may be limited to volunteer support or intermittent social work visits; others may involve nursing care.

As a result of bridge programs, a broader population of patients and families can benefit from the expert interdisciplinary care focused on symptom management along with patient and family support provided by hospice teams. These programs can also facilitate a transition to hospice care when the patient is eligible and desirous of hospice support.

**Palliative Care Consultative Model**

Palliative care consultations are generally offered as extensions of a growing number of hospital-based palliative care programs. These may be provided in a clinic setting or performed as home visits in which the palliative care team might partner with a community nursing or hospice agency. There is variation in the populations served, as well as the way programs are structured and reimbursed. For example, palliative care may be provided to patients who had been followed on the inpatient palliative care service, those referred by primary care or specialists, or those identified as high risk for readmission by the hospital.

**The Palliative Care Home Visit**

Visiting patients in their homes affords the provider a very different perspective on the patient’s life. Seeing patients in their own environment, allows the provider to directly assess the functional status of a patient, meet family members and caregivers, and conduct a family meeting in a setting familiar and comfortable to the patient and family. Seeing a patient...
within their own home also provides a unique opportunity to observe the conditions in which the patient lives and who lives with them, who provides care, or who is available for support. These observations can give insight into the patient’s past, their current functional status, caregiving needs, medication adherence, access to food, family dynamics, cleanliness, and safety of the home as well as safety of the neighborhood and access to pharmacies and groceries.

Conveying respect and asking permission are especially important in the home visit. Questions such as “May I sit here?” or “Where would you like to talk first?” are essential and convey respect and attentiveness. The provider should recognize that they are entering the private space of another at all times.

Given the nature of seeing patients at home, patients and families may seek to create a more social atmosphere for the provider, including offering food and drink. In some cultures, this is a very important ritual and to refuse may be offensive. The provider must remain focused and alert first to the needs of the patient and goals for the visit and skillfully manage the time spent in other activities.

During the home visit the provider should define a specific goal or reason for the appointment to substantiate the need for the visit (medical necessity) and the reason it is occurring in the home setting. This information helps to justify the appropriateness of billing.

The content of the home visit will differ depending on the provider; however, the structure of the visit should remain the same whenever possible, for both the initial evaluation and during follow-up visits. Maintaining consistency can be a source of reassurance for the patient and his or her family.

Indications

There are a variety of reasons that patients may require a home visit rather than make the trip to a clinician’s office. These include:

- The patient’s immobility, cognitive impairment, or a serious psychiatric condition
- A request instigated by a home health team member, the patient, or the patient’s family member
- The importance of meeting the patient with his or her caregiver in order to make medical decisions

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• The opportunity to directly observe the patient in his or her home environment to better assess the patient’s functional abilities, the caregiver’s understanding of the complex medical issues present and ability to meet the patient’s needs, and/or to verify eligibility for services by third-party providers
• The need to meet with community-based providers on-site
• The ability to assess care coordination and transitions of care in order to reduce hospital readmissions.

Before the Visit
Because of the setting, it is essential to prepare in advance for the home visit:
• Call ahead so that the patient and caregivers are expecting you
• Review the patient’s medical records (including the notes of other providers), and bring any supplies you may need
• Review the patient’s primary diagnosis and comorbidities (if present), including his or her past and anticipated course during home palliative care
• Understand the reason for referral and the home visit
• Develop a preliminary care plan, including identification of any areas that may need follow-up, review, reassessment, or reinforcement. (Plan to create a more complete care plan at the end of each visit, integrating the patient’s and family’s direct input.)

Adopting a systematical approach before the visit can help ensure that the visit will be effective and efficient, and reduces the likelihood that some important aspect (eg, medication review) of assessment or care is not performed15.

During the Visit
A standardized checklist should be used during each visit to ensure no areas of concern are missed. While elderly patients may require a comprehensive geriatric assessment, all patients should be assessed for the following:

Symptoms: During the visit, the clinician can assess and observe for symptoms such as pain, dyspnea, nausea/vomiting, fatigue, depression, anxiety, diarrhea, and/or constipation. Where possible, symptom assessment should use validated scales, including visual analog scales, to help convey symptom severity.

Functional status: Being present in the home provides the opportunity to observe the patient’s ability to complete activities of daily living and what formal or informal assistance devices they use about their home (e.g., walker, bedside commode).

Physical safety: The clinician should assess for obstacles that may increase the patient’s risk of injury (including inadequate lighting, clutter and throw rugs). For patients on oxygen, this also includes evaluation of electric cords and tubing. Based on the safety review, the clinician may make recommendations about the need for assistive devices or a hospital bed aimed at easing transfers and preventing falls. This includes evaluation of the patient’s ability to ambulate and perform activities of daily living. Finally, it includes evaluation of electric outlets to ensure there is low risk of overloading.

Medication safety and storage: In addition to routine medication reconciliation, clinicians should review where patients keep their medications and how they take and dispose of them, including oral therapies and cutaneous
patches. Ensure there are no medication errors, duplications, and issues with safety to others in the home, particularly children.

**Nutrition:** An evaluation of food and fluid availability, access to meals, and ease of availability to nutrition should be performed. It may include assessments of the kitchen and pantry, so the clinician can assess for food safety, storage, and freshness. This is particularly important for patients who appear to be left at home alone for long periods of time.

**Social support:** Clinicians should check in with caregivers regarding caregiver burden and the need for support and respite to ensure the patient has adequate home care support, and note if there is possible evidence of neglect or abuse.

Clinicians should recognize that entering a patient’s home can result in the patient (and his or her family) feeling a heightened sense of vulnerability and a fear of judgment. In our experience, acknowledging and affirming what they are doing appropriately can help ease these feelings and enhances trust and openness on both sides. Even after the death of a loved one, family members have commented on how helpful and affirming this can be.

Prior to leaving, ensure that any questions have been answered and that a follow-up evaluation is scheduled. We find it useful to facilitate teach-back to ensure key information has been effectively shared. This can be done quite simply with one or two questions, such as: “Can you tell me what you’ve taken away from my visit today?” and/or “What are you going to tell your family we covered today?”

Just as in an office visit with an outpatient provider, patients and families appear to benefit from a verbal and written review of any recommendations or changes that were made as a result of the visit which also lie at the heart of CMS’s **Meaningful Use Clinical Quality Measures**.

Although the patient’s and/or family’s needs are central to each home visit, it is not infrequent that clinical or social changes may have occurred between visits. This may require that the goals of any visit be continually updated. In addition, the assessment of one provider can help to inform the goals of others on the interdisciplinary team and prompt the need for follow-up by others on the team.

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For example, the caregiver expressing anxiety and fear may naturally allow the introduction of the social worker or chaplain. As another example, the patient’s physical complaints to the social worker or expressed concerns regarding medications to the chaplain can prompt a physician or nurse practitioner visit for further diagnosis and treatment. Such interactions are not only important but may lend more insight into the visit, no matter what the previously defined goals were.

**Advance Care Planning**

Caring for patients at home provides a unique opportunity to establish relationships with them and their families in order to facilitate ongoing discussions around advance directives, including documentation of the patient’s healthcare proxy and stated preferences around resuscitation. Once established, goals of care should be documented in the medical record, and the documents themselves should be readily available in the patient’s home.

Patients (or their decision-makers) who have clear and stated DNR preferences already documented in their living wills and other advance care planning documents should make certain that a physician-signed document (e.g., DNR order or POLST) has been completed and available in the home because these are the medical orders that emergency workers will follow if they are called.

These documents provide an opportunity for health care professionals and patients to document patient’s preference around resuscitation, medical interventions, artificial nutrition/hydration, and antibiotics as a medical order. These orders are honored by emergency medical staff as well as by nursing home and hospital staff and can ensure that patients’ preferences regarding their care are followed as they transition through or are evaluated in different care sites.

**Staff Safety**

It is important that an evaluation of the patient’s home also address the clinician’s safety in the home or in the neighborhood. This is particularly important in situations when members of the interdisciplinary team feel unsafe in a neighborhood or home, especially in the event of an urgent visit after hours.

Organizations typically provide security personnel to accompany the providers who have to make visits in areas where they do not feel safe, especially after hours. Other safety precautions include scheduling visits for daytime, using a team to allow for joint visits, gaining knowledge about the community in which visits are conducted, and having a cell phone and emergency line available. If the team feels that despite taking extra precautions the visit is unsafe, plans should be made to refer the patient to the appropriate outpatient setting for care.

**Communication and Care Coordination**

Caring for a patient in the home requires addressing many medical and psychosocial needs and this, in turn, may require the provider to establish relationships with other available community resources (e.g., mental health services, caregiver support services).

It also requires communication between all those involved in the patient’s care, including clinicians, formal caregivers (i.e., trained and paid personnel) and informal caregivers (friends and/or family). Part of this is ensuring that all caregivers know whom to contact with questions and whom to notify in the case of an emergency or...
Unfortunately, most caregivers are poorly prepared for what this entails. In a focus group...

change in clinical condition. This can be done by:

- Ensuring patients have access to a formal triage system
- Coordinating care between the involved clinicians to establish one contact person
- Increasing the involvement of social workers and care coordinators who accompany the patient and family to the hospital and/or visit regularly, as well as the establishment of relationships with visiting nurse agencies and other home care agencies for post-hospitalization care.

When hospital evaluation or higher level care is needed, clear communication with hospital teams allows for the sharing of medical history and previously established goals of care. Communication can be done through an integrated medical record (if the healthcare system between inpatient and outpatient services is the same), written information, or electronic sources (eg, encrypted email).

The Role of Caregivers

Caregivers usually help with activities of daily living such as bathing, dressing, transferring, toileting, and eating, as well as instrumental activities of daily living such as grocery shopping and meal preparation. Such services can be provided informally by unpaid family members and friends or formally by privately hired workers.

Individuals who provide personal assistance services in the community are referred to by different titles including: home care aides or workers, home health attendants or aides, and personal care aides. In the U.S., home healthcare workers cannot administer enteral feeds or medications, especially if they are paid for by commercial entities. Those caregivers who work for a licensed home health agency usually receive some supervision by visiting nurses. In addition to overseeing the care of homebound patients receiving long-term care, visiting nurses may be involved in patient’s care when skilled nursing need is required. Skilled home care nursing is typically funded through Medicare. Physical, occupational, speech, and respiratory therapists are also available to attend to acute patient care needs.

Patients receiving home palliative care often rely on family and friends as caregivers. Unfortunately, most caregivers are poorly prepared for what this entails. In a focus group...

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conducted by the United Hospital Fund’s Families and Health Care project, caregivers reported lack of information about patients’ diagnoses, prognoses, treatment plans, side effects of medication, and symptoms to monitor, as well as whom to call with questions or concerns²⁰.

Burden of Caregiving

Informal caregivers (e.g., family and friends) caring for a loved one at home are at risk for significant emotional, physical, and financial stress. As many NHPCO members well know, studies have demonstrated that caregivers — especially those perceiving the work as stressful — are at increased risk for heart attack and death⁷,²¹,²². It has also been shown that the burden of caregiving can be reduced by good communication with providers²³, the assistance and support of an interdisciplinary team, and educational programs²⁴.

In addition to education and support provided to caregivers by the interdisciplinary team, tools are available to assess for caregiver burden, such as the Zerit assessment²⁵. This caregiver self-report questionnaire asks caregivers a range of questions and is available in a variety of languages²⁶.

Well-coordinated, interdisciplinary care can have a positive impact on caregiver burden. One study found that involvement in an interdisciplinary home-based primary care program led to decreased unmet needs by caregivers, related to daily chores and transportation needs, and decreased caregiver burden²⁷. A study of the effectiveness of an outpatient palliative care team providing interdisciplinary care and care coordination also showed that this support lowered caregiver burden, anxiety, and depression, and led to increased perceived quality of life amongst both patients and caregivers¹². A systematic literature review of patient and caregivers receiving home-based palliative care found that the most frequently reported unmet need was effective communication with health care providers. Other identified unmet needs included psychosocial, practical, informational, and respite.

Coverage for Home-based Palliative Care

Changes in the Medicare reimbursement system penalize hospitals for readmissions that occur within a 30-day time frame. As a result, there is an increasing incentive to continue support for patients with chronic illness across settings of care, as they most often represent the high-acuity, high-cost portion of medical spending. This has led to increased interest in home-based care programs, particularly for patients who are facing a serious or life-threatening illness.

Unfortunately, the fee-for-service model of reimbursement in the U.S. is insufficient to support home-based palliative care. Given the prominent need for care coordination and the interdisciplinary model of care, new financial models that involve per-member, per-month reimbursements (or shared savings) are being evaluated as effective means to support this delivery of care. This payment system aligns incentives with what is meaningful care for patients and families, and better addresses efforts to provide population health management. Payment reform in this area is in the early phases and is aligned with changes on a national level.

Initiating Referrals

In the U.S., insurance carriers and healthcare services are developing algorithms to help identify high risk patients based on combinations of claims data, healthcare utilization,
and prescribed medications. For example:

- Home-base palliative care programs may work alongside home health agencies to identify appropriate patients for palliative care services. This may include patients with end-stage conditions such as congestive heart failure, chronic obstructive lung disease, serious neurological conditions (e.g., Parkinson Disease, dementia, multiple sclerosis, Amyotrophic Lateral Sclerosis), and end-stage cancer.

- Referral may also be triggered based on diagnosis plus high healthcare utilization (repeated hospitalizations or emergency room visits) or issues related to medication adherence.

- Patients may also be identified by home health providers, particularly when the skilled benefit of home care is ending and patients may be particularly in need of continued home assessment, management, and support (see ‘Home Health-based Model’ described earlier).

- Inpatient palliative care programs may continue to follow patients as they transition from the hospital setting to the post-acute setting (see ‘Palliative Care Consultative Model’ described earlier).

### Death in the Home

When possible, family members and caregivers should be counseled on what to expect when the patient in the home appears close to death. As hospice professionals well know, this should include:

- A review of advance care planning
- Ensuring that appropriate documents around life sustaining treatment preferences are readily available in the home
- Asking if family or caregivers would like to hear about specific changes they might observe during the dying process
- Making sure that a provider is available by phone for questions or concerns the family or caregivers may have.

For patients near death, the interdisciplinary team can help families prepare by facilitating funeral arrangements (e.g.,

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having the number of a funeral home on hand) and beginning bereavement screening and support. In the U.S., the laws and regulations around responding to a death at home vary, sometimes within individual counties of a state. Therefore, the provider should be familiar with the local regulations regarding death in the home. In addition, it is important that any group providing home-based palliative care and caring for patients dying at home be familiar with the regional regulations within their practice area.

When death occurs, the care plan should focus on the family. The provider must be attentive to the needs of the family and help facilitate the necessary logistics such as the pronouncement of death, the removal of the body, and the necessary documentation. However, these logistics should be sensitively facilitated so that the family does not feel rushed or stressed. Just as in hospice, care after death includes:

- Honoring the spiritual and/or cultural wishes of the diseased person and their family/caregivers while ensuring the legal obligations are complete
- Preparing the body for transfer to the mortuary or funeral home
- Offering family and caregivers present the opportunity to participate in the process and supporting them to do so
- Ensuring that the health and safety of those who come in contact with the deceased are protected
- Honoring wishes for organ, tissue, or body donation
- Returning the deceased person’s personal possessions to their relatives

At death in particular, there may be rituals, customs, or religious rites that are very important to a family that should be supported. In fact, asking family members this very question (“Are there any rituals or customs which are important to you to that we should attend?”) may be helpful at this difficult time.

### Summary and Recommendations

- Patients who benefit from home-based palliative care are typically those with advanced complex illnesses or life-limiting diagnoses and a high risk of morbidity and mortality. These individuals most often do not have a predictable prognosis and are not eligible for or interested in electing formal hospice services.
- Home-based palliative care services may be offered as part of a geriatrics or primary care practice with expertise in palliative care (primary and palliative care), or through home care (home health-based), hospice agencies, or a hospital-based palliative care program.
- During the home visit, the clinician should define a specific goal or reason for the appointment to substantiate the need for the visit (medical necessity) and the reason it is occurring in the home setting. In the U.S., this information helps to justify the appropriateness of billing.
- It is important that an evaluation of the patient’s home also address the clinician’s safety in the home or in the neighborhood.
- Adopting a systematical approach before the visit can help ensure that the visit will be effective and efficient and reduces the likelihood that some important aspect (e.g., medication review) of assessment or care is not performed.
- Caring for patients at home provides a unique opportunity to establish relationships with patients.
and families in order to facilitate ongoing discussions around advance directives, including documentation of a patient’s healthcare proxy and stated preferences around resuscitation. Once established, goals of care should be documented in the medical record. In addition, these documents should be readily available in the home.

- Caring for a patient in the home requires addressing many medical and psychosocial needs. It is important when providing home-based palliative care to learn about and establish relationships with available community resources.

- Informal caregivers (e.g., family and friends) caring for a loved one at home are at risk for significant emotional, physical, and financial stress.

- When possible, family members and caregivers should be counseled regarding what to expect when it is anticipated that a patient in the home is close to death.

Martha L. Twaddle, MD, has more than 26 years of experience in the hospice and palliative care field, and currently serves as senior vice president of medical excellence and innovation for JourneyCare. She also leads a palliative innovation practice, Aspire Health - Illinois, lending her expertise and vast experience to strengthen and define palliative care’s role within the healthcare system.

Elizabeth McCormick is assistant professor of geriatrics and palliative medicine at Mount Sinai Medical Center, and serves as a practicing physician at Mount Sinai Hospital.

References on next page
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We invite you to check out the National Hospice Foundation’s new website!

Learn about the programs you support. Interested in becoming a fundraiser? Honor and remember someone special.

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www.nationalhospicefoundation.org
Palliative Care Innovators

The 2014 Circle of Life Award Honorees

For over a decade, the American Hospital Association (AHA) has presented the prestigious Circle of Life Award® to honor innovation in palliative and end-of-life care.

This year, the AHA presented the award and a citation of honor to the following four organizations, noting their exemplary skill in actively creating and championing palliative care within the care continuum. Of particular note is winner, Lehigh Valley Health Network, which has been an NHPCO member since 1981.

Award Winners:

Baylor Health Care System Supportive and Palliative Care Services
Dallas, Texas

Lehigh Valley Health Network
Allentown, Pennsylvania

Yakima Valley Memorial Hospital and Foundation
Yakima, Washington

Citation Winner:

Center for Palliative and Supportive Care Ambulatory Program, University of Alabama
Birmingham, Alabama

NHPCO and the National Hospice Foundation are proud sponsors of the Circle of Life Award.

To learn more about the award and these winners, visit Circle of Life Award Winners on the AHA website, or see the 2014 Circle of Life Award booklet.
A Closer Look at Lehigh Valley’s Work

Lehigh Valley Health Network’s Palliative Care Program started from humble beginnings in 1999, when senior physicians received a grant for an inpatient palliative care consulting service and another specifically for the ICU. Since then the program — called “OACIS” for Optimizing Advanced Complex Illness Support — has grown to encompass a full continuum of care, with an inpatient consult service, outpatient clinic and home visits.

Using strong linkages with primary care, the program reaches patients early in diagnoses for illnesses such as dementia, Parkinson’s, MS, congestive heart failure, COPD, and cancer. “We’re seeing some patients for three to five years,” says Gretchen Fitzgerald, CRNP. “The average length of stay is 18 months.”

“To learn more about the program, see page 7 of the Circle of Life Award booklet.”
A New Way to Access NHPCO Expertise:
NHPCO Consulting

As the largest organization leading the way in hospice and palliative care in the U.S., NHPCO is always looking for ways to increase its services and share its expertise. This month we are pleased to announce a brand new service: NHPCO Consulting.

NHPCO Consulting will offer the following to both member- and non-member organizations:

- Strategic Planning
- Market Analysis
- Business Plan Development
- Media and Social Marketing Audits
- Feasibility Studies
- New Hospice Startup Planning
Deepening Relationships With Providers

As a member services organization, NHPCO has always sought to offer a broad range of services to members with an ethic of generosity. Surveys of the membership over the past year have shown a need for more individualized management consulting.

If your organization could use help with market analysis, social marketing, media outreach, or budget development, NHPCO’s experts in the specialized fields of hospice and community-based palliative care can now be at your service.

NHPCO Consulting is a new way to tap into the expertise of our staff and consultants on a host of operational, regulatory and strategic issues, and to come away with an action plan tailored to your organization. Our goal is to ensure that our relationship with providers is not only broad, but deep.

No Change to Member Services or Dues

With the addition of NHPCO Consulting, there is no change or limitation to the roster of existing member services. Consulting services are meant to complement what NHPCO members already use and enjoy. Our staff remains available to take calls and questions whenever members need help.

Because of the customized nature of NHPCO Consulting, each project will be unique, with costs borne by the individual provider engaging our services. As an added benefit of membership, NHPCO organizational members will receive a 10 percent discount on all services offered by NHPCO Consulting.

Expert Management

This consulting service is being administered by Sue Lyn Schramm, MA, who has more than 20 years of experience in healthcare consulting and hospice administration.

Prior to joining NHPCO in 2014, Sue Lyn managed a hospice strategic consulting practice that served many of the largest hospice providers in the mid-Atlantic region. In addition, she has held executive roles at several large hospice and palliative care organizations, so she knows the business both from an insider’s and outsider’s perspective.

Sue Lyn is supported by the other staff experts at NHPCO, plus a growing network of independent hospice consultants and retired executives. Each engagement will assemble a team of nationally recognized experts and industry leaders to meet the needs of clients.
**NHPCO Consulting Can Help Motivate and Inspire Board and Staff**

The work NHPCO Consulting performed for Good Samaritan Hospice this past summer is but one example of how the services can help individual organizations.

Good Samaritan is a freestanding not-for-profit provider in Roanoke, Virginia, with deep roots in its community. Like many hospices, Good Samaritan has recently seen new sources of competition for patients and changing relationships with referral sources. Good Samaritan’s leadership wanted help gathering market share and competitive information, but also wanted to make sure that market data weren’t collected only to rest on a shelf. The goal? Develop a usable action plan for outreach to new market segments and continue to position itself strongly as the leading provider of hospice care in the 14 jurisdictions it serves.

NHPCO Consulting performed a custom analysis of demographic and Medicare Hospice claims data to present competitive trends, and compared Good Samaritan’s own internal statistics to NHPCO benchmarks with similar hospice providers across the country. NHPCO Consulting was able to point out several specific opportunities for Good Samaritan to reach underserved areas and populations. Perhaps just as important, NHPCO facilitated on-site discussions with the hospice board and staff, presenting the new information in context. Staff members responded immediately to the concrete material showing how their own actions affect the health of the overall organization. By day’s end, the team had begun to generate ideas for new ways of working with referral sources to encourage better and faster customer service.

**NHPCO Speakers Bureau**

Sometimes clients don’t need a full-blown engagement with customized research and analysis, but they could use an up-to-date briefing, incorporating NHPCO’s deep knowledge of industry trends and regulations. That’s where the new NHPCO Speakers Bureau comes in. The NHPCO Speakers Bureau can send a polished and deeply knowledgeable presenter to your next Board retreat, executive planning meeting, or corporate meeting. Our speakers are available to both members and non-members, but as with NHPCO Consulting, NHPCO members will receive a discount off the NHPCO Speakers Bureau’s standard speaking fees.

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**CONTACT NHPCO TO TALK ABOUT HOW WE CAN HELP**

If you could use direct access to NHPCO’s industry-leading expertise, contact Sue Lyn Schramm for an initial needs assessment:

**Sue Lyn Schramm, MA** • Director, Consulting Services • 703-837-3147
sschramm@nhpco.org • www.nhpco.org/consulting

There’s never a charge until a client signs off on the work to be done. We welcome the opportunity to explore how we can help each and every provider organization be the best that it can be.
As demand for cost-effective health care increases, so are the expectations for improved performance in the delivery of hospice and home health services. Simione Healthcare Consultants are leaders in supporting these efforts for nearly 50 years, engaging hospitals, health networks, agencies and other providers to improve quality, reduce cost, and minimize risk for more effective patient care. Simione's teams excel in driving results across the health care continuum with expertise in:

- Operations
- Compliance & Risk
- Finance
- Sales & Marketing
- Information Technology
- Mergers & Acquisitions

Hospice & home care business solutions

Operations
Compliance & Risk
Finance
Sales & Marketing
Information Technology
Mergers & Acquisitions

Get more insight at 844.293.1528
info@simione.com or simione.com

National Hospice and Palliative Care Organization’s
CREATING THE FUTURE of PALLIATIVE CARE:
A VIRTUAL EVENT
Feb. 18–19, 2015

Register now for this virtual event and walk away with what your program needs to begin or enhance community-based palliative care services.

Hear from experts like Russell Portenoy, MD and Joan Harrold, MD, who will share “lessons learned” during the development of their own palliative care programs. Explore:

- “Best Practices” in the Development of Community-based Palliative Care Services
- Successful Models of Community-based Palliative Care
- Legal and Regulatory Considerations
- Quality and Fiscal Metrics
- Documentation, Coding and Billing for Services
- Barriers and Opportunities for Developing a Continuum of Care
NHPCO launched the Hospice Manager Development Program (Hospice MDP) in 2004 to help prepare managers specifically for their work — and the challenges they face — in the hospice setting.

Among the program’s most popular courses is the module, Ethics for Hospice Managers, which was developed by Paul Longenecker, RN, MBA, PhD, and Marion Keenan, MA, MBA, and has been offered since 2005.

As the Hospice MDP celebrates its 10-year anniversary, Dr. Longenecker, who has taught the module since its inception, looks back on the ethical issues raised by module participants during their group discussions and examination of case studies. It’s a very interesting review of how the changing landscape of health care and hospice has affected the ethical aspects of practice. (To learn more about the Hospice MDP, see page 33.)
Approximately 1,000 hospice managers have participated in the Hospice MDP’s Ethics Module since it was introduced in 2005.

The four-week module begins with a review of ethical principles, then moves into discussions about common ethical dilemmas that arise during the delivery of care as well as in hospice management. To help get the most out of the learning experience, the group discussions revolve around case studies that are presented for examination and resolution.

It was a fascinating process to compile the remarks and feedback of participants over the past nine years in which the module has been offered. While the module has been taught in both the classroom and online settings, this article shares feedback from the online participants, organized under the key area covered over the four week period: Ethical Concepts (i.e., principles and theories); Common Ethical Dilemmas; Business Ethics; and Hot Topics (i.e., emerging issues in health care).

**Ethical Concepts**

Since the module was first introduced, the “patient’s autonomy” has continued to top the list of the most challenging ethical concepts hospice managers face.

This autonomy, which focuses on the patient’s ability to outline his or her own plan of care, can pose an ethical challenge when hospice managers and their staff do not agree with the patient and family’s chosen course of action. This conflict normally surrounds the ethical concepts of beneficence (doing good) and non-maleficence (not doing harm). Although the decision and choice of action rests with the patient as long as he or she is competent, the hospice team may not believe the decision is in the patient’s best interest. Educating and supporting the patient through the decisional process appears to be at the heart of allowing the patient’s autonomy to be expressed.

In more recent years, module participants have cited the principles of veracity (truth-telling), beneficence and non-maleficence as particular challenges because, in many cases, these principles compete with one another.

For example, in respecting patient autonomy, telling the truth may cause potential harm and may not be beneficial for the patient. Also, a decision that a patient makes may cause him or her direct harm. As expressed by module participants, the ultimate challenge for hospice managers and their teams is to understand
the obstacles from an ethical perspective and be prepared to objectively address them. This process can involve education and self-exploration of each individual’s moral beliefs that may interfere with the delivery of care.

**Common Ethical Dilemmas**

The dilemmas routinely voiced by module participants seem to center around three key areas: staff boundaries, patient compliance/adherence, and futile care.

When examining staff boundaries, exploring the questions at the very heart of this issue is valuable: Is this a hospice personnel issue related to staff (or volunteers) being unable to set appropriate boundaries with patients and families? Or is this an issue of hospice managers not educating and enforcing the boundary policies that are in place? When presented as outlined, the discussion can be very enlightening as module participants analyze where their organization fits on this continuum.

Where feedback has changed is in the area of compliance. In the early years of the Ethics Module, discussion of compliance focused more on the plan of care being developed by the hospice team, with non-compliance meaning the patient was not following the plan of care that was developed for them. In recent years, the focus has shifted away from compliance to become more about adherence to the plan of care that is jointly developed by the hospice team and the patient. This subtle difference has generated increased discussion among module participants, and the introduction of the concept of adherence has helped lessen the ethical impact of any caregiver/patient differences.

Lastly, the topic of futile care continues to be an elusive ethical issue, namely because futile care continues to have different meanings based on where hospice programs are located. When course participants from different parts of the country compare notes, one of the key questions that arise is “who defines what is futile?” Is it the patient, the family, the physician, the insurance company, or society? With the introduction of insurance policy changes, especially since the Affordable Care Act took effect, the course discussions have taken on new points of interest.

**Business Ethics**

In the early years of the Ethics Module, many participants did not perceive themselves as very involved in the business side of their organizations. Interestingly, this perception appears to still hold true.

The primary method we use in the module to explore business ethics is through case analysis of business-related topics, although the focus of the business related cases has changed. Module participants are asked to analyze one of two cases: one relating to contracts or another relating to artificial nutrition and hydration (ANH). They are then asked to post their analysis of the case, respond to each other’s posts, and note whether other participants’ posts changed their opinion about the case.

Interestingly, the ANH case is routinely selected three to four times more often than the contract case, regardless of whether the module participants come from the clinical or business side of the hospice. It would appear that even though hospice care delivery has taken on a stronger business model over the last decade, hospice managers’ perceptions of their role in business operations — and the ethical challenges confronting their organizations in this area — have not evolved along with the changes.
**Hot Topics**

It is in this portion of the module where the perceptions of participants have really changed in recent years.

For example, in 2006, ANH was familiar to module participants, although admittedly challenging; palliative sedation, on the other hand, was completely unknown.

Today, both ANH and palliative sedation are familiar topics, with module participants having had specific experience with addressing the dilemmas that arise during policy development and utilization. Although the ethical dilemmas associated with these issues have not gone away, module participants have become far more comfortable with confronting them.

Another area of change relates to pediatric care, appearing to replace palliative sedation as ‘unknown territory’ among module participants. This of course is not surprising, given that pediatric hospice care is truly specialized care. In fact, NHPCO Facts and Figures reports that just 0.4% of all hospice patients served are age 24 or younger.

Pediatric hospice care appears to introduce a few key challenges to the application of ethical concepts. With pediatric patients, the issue of “competence” impacts autonomy since the patients are not able to express their wishes themselves. Issues of doing good (beneficence) and avoiding harm (non-maleficence) when related to children also appear to change the focus of the analysis and the willingness and desire to do more. Veracity (truth-telling) appears to create a large barrier to sharing information due to a fear of taking away hope. Although pediatric hospice care is not an area of care delivery that most module participants perceived as part of their care delivery model, group discussions of a pediatric case typically generate many different perspectives on the ethical principles involved.

**Some of the Module Takeaways**

Since the Ethics Module was introduced nine years ago, the limited use of a hospice ethics committee has been cited as a key obstacle among participants. Back in 2006, I had observed that ethics committees within hospice programs were not as common as I had anticipated. Unfortunately, this observation appears to still hold true. Although no specific statistics were collected on the topic, the number of managers that identified the presence of an ethics committee in their hospice has shown little change. In addition, it was noted
that in hospices with ethics committees, many had no formal mechanisms for educating their committee members on ethical analysis or providing ethics training to their staff.

Although the absence of ethics committees is a concern to me, it's always uplifting when I see, as part of the course evaluation, the number of module participants that identify the need for creating an ethics committee, better utilization of their ethics committee, and utilization of the course case analysis tool by their ethics committee. Many module participants have also expressed a willingness to help start an ethics committee or serve on the ethics committee of their organization.

Another common takeaway among module participants is the desire to apply an ethical perspective to the issues and challenges they face in their practice. Many have noted their “new ability” to focus more on objective analysis of the issues rather than take a subjective approach. In addition, many have reflected on the importance of viewing issues from a broader perspective rather than focus only on the clinical impact.

**In Summary**

Only minor variations have been noted over the nine-year period in which the Ethics Module has been offered, namely increased use of palliative sedation and pediatric care, and a stronger utilization of a business model requiring a need for more awareness of ethical concepts. These variations seem to follow the changing trends of end-of-life care in the U.S. (i.e., increased patient/family involvement and continued advancements in technology and treatments), and have resulted in issues that impact ethical hospice care delivery.

Paul D. Longenecker is the senior instructor in the Department of Health and Sport Sciences at Otterbein University in Westerville, OH. Prior to joining Otterbein, he was assistant professor in the College of Business & Leadership at Lourdes University in Sylvania, OH. In addition to his nine years of academic experience, where his research focus has been on hospice organizational culture, leadership and ethics, he also has over 35 years of experience in the healthcare industry, having served as a clinician, manager, executive and consultant.

The author extends special thanks to Marion Keenan, MA, MBA for assistance in providing needed information for this article. To download the complete copy of Dr. Longenecker’s article on this topic — click here.

**Free Member Resources**

The NHPCO Ethics Advisory Council has developed a range of resources to assist members, including position statements on Ethical Marketing Practices; Artificial Nutrition and Hydration; Palliative Sedation; and Palliative Care in Critical Care Settings.

See Publications-Press Room on the NHPCO website to review or download these resources.
Many hospice managers have either risen up within an organization and have little management training or they are brand new to the hospice field. They need training on how to perform as managers within the hospice interdisciplinary team. This is where the Hospice Manager Development Program (Hospice MDP) can help.

The Hospice MDP is a comprehensive program that is divided into three levels:

- **Level 1** requires completion of a two-day face to face foundational course and two online learning modules
- **Level 2** requires completion of six online modules
- **Level 3** requires completion of additional enhancement modules as well as self-study and an independent learning project under the direction and guidance of an NHPCO leadership coach.

The two-day, *face-to-face* foundational course addresses hospice leadership and management principles. Once the foundational course is completed, participants can take additional Level I and Level II online modules that delve more deeply into specific application of the principles.

**CEUs and Certificate of Completion**

The Hospice MDP foundational course and companion modules have been approved to provide credit for nurses and social workers. NHPCO has pursued credit for the disciplines of spiritual caregiver and counselor, but the Hospice MDP has not been approved to provide continuing education credit for these disciplines.

When participants complete all of the modules that comprise a level, they are awarded the Hospice MDP Level designation, are recognized on NHPCO website, and receive a framed certificate of recognition.

**Taking Individual Modules**

If hospice staff members are not able to enroll in the Hospice MDP, they do have the option of enrolling in specific online modules, such as the Ethics Module discussed in Dr. Longenecker’s article.

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**Learn More**

For general information about the Hospice MDP, visit [www.nhpco.org/mdp](http://www.nhpco.org/mdp) or see Frequently Asked Questions. Members can also contact the Professional Development Department: education@nhpco.org or 703-647-5178.

To get a firsthand account of a manager’s experience in the Hospice MDP, see the interview with Deborah Goodman in the March 2014 issue of NewsLine.
Meet This Year’s Volunteer Honorees

From L to R: Katharine Foster; Betty Takes; Margi Miller; Clarence Smith.
NHPCO sponsors the annual “Volunteers are the Foundation of Hospice” Award to shine a national spotlight on volunteers who have demonstrated a remarkable level of service, compassion and commitment to the hospice community.

The 2014 award winners were recognized during the Clinical Team Conference that just concluded in late October — and their contributions to hospice care are indeed inspiring....

For Patient and Family Service:

Clarence Smith
Beacon Hospice, an Amedisys company
South Portland, Maine

As a Korean War veteran, Clarence Smith joined Beacon Hospice in 2007 with the goal of supporting veteran patients with PTSD. While he has been a key contributor to Beacon Hospice’s work as a We Honor Veterans partner, this octogenarian has also willingly helped patients, families and staff wherever the need was greatest, and this quality, above all, continues to inspire those who know him.

When the hospice needed volunteers to provide companionship to dementia patients, Clarence stepped up immediately, taking additional time to learn about the complex disease so he could provide the best support possible. When staff needed a “Cupid” to deliver valentines to 100 patients, Clarence was on it (and with good humor). He also serves as both a vigil volunteer and bereavement volunteer, and has always been willing to put his own day’s plans aside to be there for patients and families. Since 2008, he has contributed more than 1,200 volunteer hours.

For Organizational Support:

Elizabeth “Betty” Takes
Hospice of Dubuque
Dubuque, Iowa

Betty has dedicated 36 years of her life to Hospice of Dubuque in both professional and personal capacities. “I cannot think of Hospice of Dubuque without thinking of Betty,” says Executive Director Lavonne Noel. “Without her, this organization would not exist.”

Noel means that literally. When Betty returned to nursing school in 1978 to earn her BSN, she was assigned a “change project” that involved implementing a community-based hospice program. Having already worked as a registered nurse for 18 years, Betty remembered the many faces of patients dying in the hospital and their desire to go home — so

continued on next page
this project resonated deeply with her. But completing this college project wasn’t enough. Between 1978 and 1981, she was the driving force behind the creation of Hospice of Dubuque.

In addition to this significant accomplishment, Betty spent five years as a hospice nurse followed by service as a patient care volunteer. She has also served on the Hospice of Dubuque board for three separate multi-year terms.

**For Specialized Volunteer Support:**

Margi Miller
Tidewell Hospice
Lakewood Ranch, Florida

Margi Miller joined Tidewell Hospice in 2009 and has provided more than 1,000 hours of volunteer service, almost entirely in specialty programs. “She is active in almost every specialty program we have,” says director of volunteer services, Stacy Groff.

Upon joining Tidewell, she learned to play therapeutic harp for the sole benefit of hospice patients and families, but has also volunteered in its horticultural therapy program, has been trained to provide Caring Touch, and has brought tremendous joy to patients by “sharing” her dog, Lucy, on patient visits. She also uses her technological skills to create DVDs and other life review projects in collaboration with Tidewell’s staff expressive artist.

“Each person faces their own death in a different way, one to be respected and supported,” Margi said. “Much has been given to me during my life, and now is my time to return those blessings.”

**For Young Leadership Support:**

Katharine Foster
BJC Hospice
St. Louis, Missouri

Katharine, a pre-med student at St. Louis University, joined BJC Hospice in 2012 as a patient care volunteer.

Despite a heavy class schedule, she has provided tremendous support as a companion to the hospice’s nursing home patients and to those in the very final days of life (as part of the hospice’s Passage Program). She has also served as a “cabin buddy” in the hospice’s annual Stepping Stones Camp for bereaved children.

More impressive still was her demonstrated leadership in helping to launch two programs: an OB/GYN Oncology Pilot Program to support women facing end-stage gynecological cancer, and a Transitions Program to support members of the community with a terminal illness and prognosis of one year or less.

“Every time I can convince a new volunteer to join, to tell a friend about hospice’s benefits, to sit with a new Transitions client, or share a story from my own experience, I’m working toward my personal goal of spreading the message of the benefits of hospice care,” she says.

**Special Thanks to NHPCO’s NCHPP**

These volunteer awards were created and are administered by NHPCO’s National Council of Hospice and Palliative Professionals (NCHPP), a section of the organization’s membership that promotes the contributions and skills of the different professional disciplines that make up the hospice interdisciplinary team.
# 2015 Webinar Schedule

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*Compared to individual webinar pricing.

**Denotes change from regular schedule to avoid conflicts.
Lighthouse of Hope: Helping Hospices Provide Memorable Moments

People living with life-limiting illnesses often want to reconnect with long-lost family members, revisit a favorite place, or just fulfill the simplest of wishes, such as enjoying a special dinner with a spouse or loved one. The National Hospice Foundation’s Lighthouse of Hope Fund helps NHPCO provider-members make these simple requests come true.

How It Works:

- The NHPCO provider-member must complete a brief online application, with information about the patient and the patient’s request. (The requests must support “experiences for living,” such as flying people in to visit, enjoying a special dinner, etc.)
- NHF staff will review the grant application and notify the provider-member of approval or non-approval within 48 hours of receiving the application.
- Funds are mailed to the provider-member in the amount specified on the application.
- If for any reason the experience is not granted, the funds must be returned to the National Hospice Foundation.

To be eligible, the patient must be under the care of the NHPCO provider-member, have a life expectancy of one year or less, and have no other means to fund the request.

To learn more, see the Lighthouse of Hope Fund on the NHF website.

Anita Adelson Hospice (Las Vegas, NV) requested $250 to help Anita, a hospice patient and longtime fan of the Jackson 5, see the late-Michael Jackson’s brothers perform at Planet Hollywood.

Wish accomplished: Last March, Anita and her husband, Samuel, were escorted by limo to a pre-concert dinner and spectacular show.
NHPCO’s New Facts and Figures Provides Insight into Access

NHPCO’s annual publication, Facts and Figures: Hospice Care in America, reports on hospice trends and provides updated information on the growth, delivery, and quality of hospice care in the U.S. NHPCO officially released the new 2014 edition at the Clinical Team Conference that just concluded in late October.

Among findings shared in the new edition is the 34.5 percent of hospice patients who died or were discharged in seven days or less, down only slightly from the year before (35.5%).

“While many dying Americans are opting for hospice care at the end of their lives, far too many receive care for a week or less,” stated NHPCO president/CEO, Don Schumacher, in a release issued to media outlets on October 27. “We need to reach patients earlier in the course of their illness to ensure they receive the full benefits that hospice and palliative care can offer.”

This sentiment is reflected in the report, Dying in America, which was recently published by the Institute of Medicine. The report also calls for greater access to advance care planning and palliative care services.


Short Takes continued on next page
Free Online Resources for Family Caregivers Available From Consumer Reports

Consumer Reports has launched an online web portal with a range of free materials for family caregivers, including information on hospice and palliative care. The goal is to provide Americans with information and tips to help them make the right decisions about a loved one’s care.

Among the materials available is a “Guide to Palliative and Hospice Care” that NHPCO was pleased to help develop.

“We are proud to partner with an organization such as NHPCO,” said Dominic Lorusso, the director of Health Partnerships for Consumer Reports. “Their focus on such important issues is right in line with the goals of the Consumer Reports health mission, which is to ensure consumers receive unbiased, easy-to-understand information when faced with difficult decisions.”

As with other items offered by Consumer Reports, the materials on this new web portal are free for consumers and their families to read, print — and share. Be sure to share the link or specific materials with your referral sources and members of your community.

A Great Side Benefit Too

This new web portal also features a link to the NHPCO campaign, Moments of Life: Made Possible by Hospice. As many members know, Moments of Life features a collection of videos of real patients and the unique benefits they receive from hospice care. Having this link on the Consumer Reports web portal is an exciting new way to reach more Americans.

Visit: consumerhealthchoices.org/caregiving/
NHPCO Unveils Mobile App for Conference Attendees

Members who were able to attend the 15th Clinical Team Conference in Nashville this past October were the first to try NHPCO’s new mobile app for conference attendees.

The new mobile app provides quick access to the latest program updates and information, and allows attendees to build their own schedules, access concurrent session handouts, evaluate sessions on-site, network with other attendees, use the interactive floor plan to navigate the Exhibit Hall, and more!

NHPCO received very positive feedback from CTC attendees on this handy new tool. It will also be used at the Management and Leadership Conference this spring — so please stay tuned!

Reminder: Invalid Diagnosis Codes as of October 1

When CMS issued CR8877 to implement the FY2015 Hospice Wage Index Final Rule, it also issued a list of “Invalid Hospice Diagnosis Codes” that should not be used as a primary diagnosis code for hospice patients with dates of service beginning on October 1, 2014 or later.

CMS has implemented a Medicare Code Editor which will send claims with any diagnosis on this list back to the provider (RTP) for recoding.

If you are not already familiar with these diagnosis codes, see the NHPCO Regulatory Alert (10/2/2014) for details and helpful links.
Rajagopal Honored by Human Rights Watch

Human Rights Watch has awarded Dr. M.R. Rajagopal of India the prestigious Alison Des Forges Award for Extraordinary Activism in recognition of his 20 years of dedicated service as a leading palliative care physician.

As a clinician, academic, and activist, Dr. Rajagopal has been a global force behind efforts to promote and put into practice palliative care as a human right. He built the world’s most successful community-based palliative care program, and he and his organization, Pallium India, played a key role in convincing India’s government to make morphine accessible.

Also receiving the 2014 award were Shin Dong-Hyuk from North Korea, Father Bernard Kinvi from the Central African Republic, and Arwa Othman from Yemen.

[Photo courtesy of Paramount Color Lab, Ulloor Trivandrum.]

Jeff Mislevy Joins Covenant Care

Jeff Mislevy has been named president/CEO of Covenant Care (Pensacola, FL), and will oversee Covenant Hospice, Covenant Alzheimer’s Services and Covenant Palliative Care.

Mislevy, who comes to Covenant Care from Spectrum Health Continuing Care, has a broad range of healthcare expertise.

NHPCA Establishes Galen Miller Educational Fund

The Nebraska Hospice and Palliative Care Association (NHPCA) has established a scholarship fund in memory of NHPCO’s former executive vice president, Galen Miller, PhD, a native Nebraskan who died in August of 2013.

[Photo of Bob Ward (second from left) with NHPCA and NHPCO leadership.]

The fund will provide scholarships for nurses, social workers, chaplains, volunteer coordinators, bereavement coordinators, and hospice aides in Nebraska who work in the end-of-life field, in recognition of Dr. Miller’s longstanding dedication to education and research.

Last April, Dr. Miller was also posthumously awarded the 2014 State Impact Award at the NHPCA Conference in Lincoln, Nebraska —the association’s highest honor. Dr. Miller’s longtime partner, Bob Ward, accepted the award on his behalf.
Kudos to Hospice of Amador & Calaveras

While Hospice of Amador & Calaveras (Jackson, CA) has been a Medicare-certified program for over 32 years, this past summer was the very first time the organization was audited by the State of California. “Two RNs appeared at our door unannounced, and spent three days making onsite visits and reviewing charts,” said Executive Director Dan Riordan.

The end result was not only impressive, but also uplifting for the staff of this small, rural program serving approximately 40 patients each day. “The RN in charge told us that for the first time in her 20 years of experience, she and her team could not find a single deficiency. Not one,” Riordan shared. “Each and every member of this hospice organization is remarkable and they really do exemplify the founding spirit of hospice while embracing all the current challenges that come with it!”

NHPCO applauds Riordan and his entire staff for their dedication and commitment to patient-centered care.
Hospice Care of South Carolina Recognized as Best Place to Work

Hospice Care of South Carolina (Spartanburg, SC) has been named one of the best places to work by Modern Healthcare.

The recognition program, now in its seventh year, honors workplaces throughout the healthcare industry that empower their employees to provide patients and customers with the best possible care, products and services.

“Receiving this award is a great honor as it reflects an unbiased response from our own employees,” said the hospice’s CEO, David Powell. “Creating an environment where employees are appreciated and opportunities are provided for professional development results in satisfied team members who enjoy coming to work and consistently deliver excellent patient care.”

Diane Hill Taylor Named Senior Vice President at NHPCO

This past September, Diane Hill Taylor, MSW, joined NHPCO as senior vice president of the Office of Education, Access and Philanthropy.

Ms. Taylor brings more than 25 years of experience to the position in the areas of strategic planning, national and state program development/management, volunteer management, community service, public health and community training. Most recently, she served as associate director for the Health and Wellness Division at the Prince George’s County Health Department where she directed programs for a number of chronic disease prevention and wellness strategies.

As senior vice president, she will provide strategic direction, leadership and innovation for NHPCO’s educational programming, and for the access and philanthropy programs of NHPCO and its affiliate organizations.
Turns out even when you’re dying, there can be a lot of living to do.

We’re showing the world how hospice makes more meaningful moments possible for patients, caregivers and families.

See their stories at momentsoflife.org
News From National Hospice Foundation

A Run to Remember
Three participants run in honor of their loved ones and in support of hospice care.

On October 12, 2014, approximately 45,000 runners participated in the 37th Annual Chicago Marathon. The National Hospice Foundation was fortunate to have eight participants running on behalf of Run to Remember, a fundraising program for NHF. A total of $18,786 was raised that day. Read more about participants Lauren Messina, Steve Searfoss and Moira Dargis.

NHF Hosts “A Night in Mumbai” and Raises Funds for Global Partners in Care

On Tuesday, October 28th, guests of the Clinical Team Conference in Nashville were transported to India for A Night in Mumbai, a fundraising event to benefit Global Partners in Care. Henna artists, a fortune teller, and Bollywood dancers set the mood, and guests were able to enjoy authentic Indian dishes. During the program, recognition was given to Hospice of Kankakee Valley as the first partnership in India. An appeal and the silent and live auctions raised money for Global Partners in Care and palliative care scholarships in Africa.

Galen Miller’s Commitment to Hospice Lives On in Many Ways

Dedicated hospice professional chose NHF as the beneficiary of his retirement plan. His gift will support the work of hospice and palliative care.

Galen W. Miller, PhD, dedicated his life’s work to advancing care at the end of life. His passion was for hospice and care of the dying and his work on behalf of hospice and palliative care at the community, national and global level serve as an ongoing inspiration to others.

Add Special Meaning to Your Gifts

It’s that time of year again when many of us will be purchasing gifts for our loved ones. The National Hospice Foundation invites you to add special meaning to your gift. Each time you make a purchase from one of the vendors listed, they will make a donation to the NHF.

www.NationalHospiceFoundation.org/Shop
Your one-stop source for Hospice Data Analytics & Benchmarking

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Global Partners in Care Celebrates First India Partnership
Hospice of Kankakee Valley Teams Up With Narikeldaha Prayas of Moyna, West Bengal

Global Partners in Care is pleased to announce its first U.S. and India hospice and palliative care partnership – Hospice of Kankakee Valley of Bourbonnais, Illinois, and Narikeldaha Prayas of Moyna, West Bengal. The two organizations will work together to expand access to hospice and palliative care in the region where Narikeldaha Prayas is located. 

Pay it Forward. Become a Global Partner Today.
Our Partner Program provides the opportunity for hospice palliative care organizations in the U.S. to support a hospice palliative care organization in another country. To help our partners engage in a wide variety of activities to expand and improve services, Global Partners in Care:
- Provides personalized consultation and ongoing technical assistance
- Wires financial donations from U.S. partners to their respective international partner
- Collaborates and coordinates with international and national palliative care associations
- Networks partners together so they can learn from each other

New Publication Available: Guidelines for Clinical Placements in Hospice and Palliative Care in Africa

Africa is facing a staggering disease burden that is only expected to increase dramatically in the coming decades. To meet this demand, African health care professionals need education and training in how to provide high-quality, culturally competent palliative care.

Global Partners in Care (formally known as FHSSA) and the African Palliative Care Association (APCA) are pleased to announce the release of their new publication, Guidelines for Clinical Placement in Hospice and Palliative Care in Africa, to help organizations implement and host successful Clinical Placements in palliative care.

From Our Global Partner Application Files

Who? HAPPY FEET HOME
What? India’s first children’s daycare hospice that provides free emotional, psycho-social and spiritual support to children with life threatening/ life limiting illnesses.
Where? Mumbai, India

Who? NYERI HOSPICE
What? Provides palliative care to patients with life threatening illnesses of cancer and HIV/AIDS.
Where? Central Kenya

To partner with Nyeri, Happy Feet Home or other international organizations in need, contact Global Partners in Care.
As a Hospice Executive Are You Looking for Critical Competitive Data to Stay Ahead of the Curve?

Look No Further… The 2015 State Hospice Profile™ contains comprehensive hospice care details for each county based on Medicare data from 2000-2013, providing the critical information needed to learn more about the competitive environment of your state.

Produced by Health Planning & Development, LLC & Summit Business Group, LLC and marketed exclusively through the NHPCO Marketplace, each 2015 State Hospice Profile™ provides vital county-level information. Full-colored charts and graphs provide information from an analysis of the last eleven years of Medicare claims data.

Here are examples of the valuable information included in the 2015 State Hospice Profile™

- Estimated Medicare Cap usage
- Major hospice providers in the county
- Comparative hospice penetration data/market share trends
- Average Length of Stay
- Distribution of hospice census

As an added bonus, each State Hospice Profile™ also contains a National and Statewide Profile of hospice care based upon Medicare claims data going back to 2000.

State Hospice Profiles™ are individually priced based upon the number of counties in each state. Please call 1-800-646-6460 for pricing details and to order. Profiles are available for all 50 States.
NHPCO gratefully acknowledges ChiPPS (Children’s Project on Palliative/Hospice Services) whose members serve as NHPCO’s pediatric advisory council and are responsible for many of these resources.

Free for Healthcare Professionals:
- ChiPPS E-Journal - quarterly publication
- NHPCO’s Facts and Figures on Pediatric Palliative Care and Hospice
- Pediatric Palliative Care Standards of Practice for Hospice Programs
- Pediatric Concurrent Care - Briefing and Implementation Toolkit
- Brochures for Families with Serious Ill Children - English and Spanish available

Education Opportunities:
- Pediatric Palliative Care Online Courses:
  - 10 Modules Available for Multidisciplinary Professionals
- NHPCO Clinical Team Conference & Pediatric Intensive:
  - Held Annually, Special Pediatric Session Track
- Pediatric Palliative Care Training:
  - Two Day Preconference, NHPCO Clinical Team Conference and Pediatric Intensive
More From **Moments of Life**

**New PSA to Promote the Campaign**

Since the launch of NHPCO’s national campaign, “Moments of Life: Made Possible by Hospice,” last spring, Americans have watched more than a dozen videos, seeing firsthand how hospice care has allowed actual patients to live more fully in the final days of their lives.

To help promote the campaign, NHPCO also commissioned the creation of a “Welcome to Moments” PSA, featuring only real patients and families in hospice. Since its release in mid-May, the PSA has aired on TV stations affiliated with CBS, ABC, NBC and FOX, reaching over 1.2 million viewers so far.

To keep the momentum going, a second PSA, “Family Picnic,” was just released in September. It features the story of Willie, the matriarch of a multi-generational family in Ohio who turned to hospice and found more joyful moments awaited her. [Watch this new PSA now.](#)

**Please Also Help Promote It!**

1. Contact your local TV and cable stations and ask for the contact information of the person who handles Public Service Announcements. Or, if you advertise with local stations, contact your sales rep and ask for the person responsible for airing PSAs.

2. Download our [one-page PDF](#) and share it with these station contacts. This PDF makes the pitch for airing the PSA and gives the station personnel the necessary link to the broadcast quality version of the PSA.

3. While you can send the PDF to station contacts via email, bringing it to an in-person meeting will make a stronger impression and allow you to reinforce your own work in the community. If you do meet in person, you might want to follow up by sending the PDF via email, with the broadcast link.

4. Reach out to the station contact a week after you send the PSA information and politely ask if he or she was able to successfully download the PSA. If any technical difficulties were encountered, please email NHPCO at [communications@nhpco.org](mailto:communications@nhpco.org).
Links to Some Resources on the NHPCO Website

**Quality and Regulatory**
- Quality Reporting Requirements
- QAPI Resources
- Regulatory Center Home Page
- Fraud and Abuse
- Past Regulatory Alerts and Roundups
- Staffing Guidelines
- Standards of Practice
- State-specific Resources
- Quality Partners Self-Assessment System

**Professional Education**
- Education Home Page
- Webinar Schedule
- Upcoming Conferences
- End-of-Life Online
- Pediatric Palliative Care

**Publications**
- Weekly NewsBriefs
- NewsLine
- ChiPPS Newsletter

**Outreach**
- 2014–15 Outreach Materials – New!
- Social Media Resources
- LIVE Without Pain Resources

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