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Managing Patients At End Of Life

The clinical team at a rural skilled nursing facility develops a palliative care program that also serves the surrounding community.

When the clinical team at Beacon Ridge—a skilled nursing and rehabilitation facility located in rural western Pennsylvania—set about designing and implementing a palliative care program, they began by identifying the basic goal of their initiative: to improve the quality of end-of-life care for both facility patients and individuals in the surrounding community using a holistic, interdisciplinary model of care.

Once this objective was established, the next step was to define palliative care. Initially, palliative care was defined narrowly as care provided to those patients formally enrolled in the facility's hospice care program. But that definition proved far too restrictive, since only about 1 percent of Beacon Ridge's patients were receiving hospice care. The team realized immediately that to embrace the spirit of their initiative, the definition would need to be broadened.

New Definitions Outlined

With this assessment and evaluation, the task became two-fold. First, staff needed to better identify hospice candidates beyond the 1 percent, since that was deemed too low. And second, the definition of palliative care and new guidelines for delineating "hospice" and "palliative" care would be required.

The team found that a critical barrier preventing access to hospice care for many patients nearing end of life was the difficulty in deciding when hospice care should actually begin. One of the criteria for the Medicare hospice benefit is a prognosis by a physician of six months or less to live, assuming the fatal disease or condition runs its normal course. This same criterion is used to define end-of-life item J5c of the minimum data set (MDS). Lack of a definitive six-month or less prognosis, along with other variables, can result in patients not having access to the hospice Medicare benefit.

> ■ Choosing palliative care means changing from curative goals to comfort goals.

Defining palliative care, team members found, called for an even broader view, as palliative care is about living and about providing access to needed care with the goal of obtaining the best possible quality of life. Patients who choose palliative care have made the decision, along with their physicians and family members, to change from curative goals to comfort goals.

Palliative care becomes appropriate when the focus on curing a patient who is dying becomes an impediment to quality of life and the patient decides not to spend his or her remaining time on aggressive, curative procedures. At such times, medical intervention is focused on symptom management—including aggressive pain control. And because pain can be experienced physically, mentally, emotionally, and spiritually, a palliative care team should be ready to intervene in any or all of these areas.

Implementing The Program

Having settled on an acceptable definition of palliative care, the Beacon Ridge care team was ready to move into the implementation phase. For expert assistance, they turned to the VNA Family Hospice of Indiana County, the community's largest hospice provider. VNA provided a palliative care nurse consultant who helped the facility to fully enact a comprehensive program. Beacon Ridge also developed a formal relationship with VNA's medical director, who agreed to serve as medical director for the facility's palliative care program.

The care team, in concert with VNA staff, then developed a set of admissions criteria for the palliative care program that encompassed two phases. Phase 1 would include cases in which an interdisciplinary assessment of a patient's condition could not reliably

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approximate when end of life might occur. Phase 2 would include cases in which an interdisciplinary assessment demonstrated end of life to be less than one month away.

Further, the program would accept only those patients who, along with their family members and the health care team, had reached a decision that further curative treatment would not succeed.

Such cases included those in which a patient's disease or condition was either a fatal, chronic illness (cancer, cardiac disease, pulmonary disease, AIDS, or multiple organ system failure, for example) or an advanced chronic disease (rheumatoid arthritis, insulin-dependent diabetes, or dementia, for example).

Pain and symptom management would become the primary goal; however, all treatment options in this phase were to remain available in accordance with client and family wishes.

Identifying Candidates

Clients enter Phase 1 of the program when interdisciplinary assessment is unable to approximate when end of life might occur.

Assessments at this stage include: 1.) appropriateness of the patient for skilled nursing or therapy services; 2.) need for referral and availability of additional support services, family resources, medical social services, and community resources; and 3.) potential need for intermediate/continuous care such as hospice services.

Palliative care in the facility setting includes measures designed to control symptoms of the disease or condition and promote comfort. An interdisciplinary approach is directed toward pain control, symptom control, emotional support, family support, and spiritual counseling.

Patients enter Phase 2 of the program when the interdisciplinary assessment demonstrates end of life to be less than one month away. Understanding that what happens during the last moments of life can have lasting effects on family, friends, and caregivers, the patient may be cared for in the Serenity Suite, a private room in the facility designed to accommodate the unique comfort and dignity needs of the patient and his or her family during the dying process. The focus of care is that the patient be allowed to die in comfort and with dignity.

The family is considered to be part of the unit of care and also receives nursing assessment and emotional support. Family contact with the patient is recognized as important and is encouraged with provisions (food, drink,

places to lie down) for a round-the-clock vigil.

The family and caregivers are encouraged to maintain physical contact such as holding hands and performing small tasks such as wiping the client's forehead with a damp cloth. Medical equipment is removed from the area whenever possible. Support personnel such as clergy or friends are encouraged to be present if the patient and family desire. Bereavement care is also incorporated into the interdisciplinary approach.

Applying A Personal Severity Index

Initially, identification of program candidates in accordance with admissions criteria was done without any formal selection process. Eventually, however, the care team decided to take a more formal approach by applying a Personal Severity Index (PSI), developed by Morris *et al.* ("Proximity to Death, a Modeling Tool for Use in Nursing Homes"), which is derived from 25 MDS items that are statistically related to the likelihood of death within six months. In this scale, a patient with a score of 9 or greater is considered to be at higher risk of death. By knowing a patient's PSI score, the care team was better able to set family's expectations and avert the emotional turmoil that often leads to inappropriate care.

After development of the palliative care program admission criteria, the standard approach to discussion of advanced directives with patients was evaluated. The facility's standard protocol included identification of a durable power of attorney and determination of the patient's desires for medical treatment at end of life.

After researching various options,

For More Information

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- Aging with Dignity: www.agingwithdignity.org.
- City of Hope Pain/Palliative Care Resource Center: www.cityofhope.org/prc.
- Robert Wood Johnson Foundation: end-of-life care: www.rwjf.org/programs.
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the facility revised its protocol to include the use of Five Wishes (a trademark of "Aging with Dignity"), the first living will that addresses personal, emotional, and spiritual needs, as well as the patient's medical wishes.

Pain management also became a key focus for clinical staff. The hospice nurse consultant played a leading role in helping staff assess and recognize symptoms of pain. She also served as a resource to provide education on current standards of practice for both the medical and clinical staff.

Education And Training

The facility team now felt ready to move forward with educational programs. It began by identifying, training, and ensuring the competency of staff members who wished to participate in the palliative care program. Current patients and family members were targeted in round two of the educational process to increase awareness of the services available at Beacon Ridge. Finally, the facility team presented community programs aimed at educating the public so that when palliative care became an option, patients and families could make an informed decision based on a full understanding of whether it was right for them.

Beacon Ridge also joined forces with other community providers to target all individuals in need of services throughout the community continuum of care. Additional community health care professionals contributed to the palliative care program to create a comprehensive approach that could be standardized as patients moved from one setting to another throughout the continuum.

Beacon Ridge's care system, which allows patients with a fatal illness to understand their prognosis and make informed decisions about their care, now serves as a model for everyone in the community. By using the expertise that already exists in the community and by working collaboratively with those same resources, every person with a fatal illness can get the help and support they need to die in comfort and with dignity. ■

Alzheimer's Caregivers Feel Responsibility

A majority of caregivers of people with Alzheimer's disease are reluctant to place their loved one in a nursing facility or an assisted living residence, according to the Alzheimer's Foundation of America (AFA), which recently released a survey of 655 individuals in the United States who are involved in care and treatment decisions on behalf of a relative or friend with Alzheimer's disease.

Indeed, the survey revealed that some 80 percent of such caregivers would not consider placing their loved one in a facility, citing that it is their own responsibility to take care of that individual. Sixty percent of those said they would feel guilty if they did not accept responsibility.

"Despite the role that assisted living facilities and nursing homes play in the continuum of care for people with Alzheimer's disease, the survey also revealed that significant proportions of African American and Hispanic caregivers don't consider [nursing facilities] an option," AFA said in a statement.

The survey found that 19 percent of African American caregivers and 21 percent of Hispanic caregivers would consider placing their loved one in either a nursing facility or assisted living residence, compared with 32 percent of caregivers of other races.

AFA reports that the survey results shed light on caregivers' knowledge and perceptions of Alzheimer's disease and explains some of the obstacles that may delay diagnosis and the impact of caregiving responsibilities on caregivers' own families and lives.

The survey results also raised some concerns about caregivers' knowledge of the disease and its symptoms, especially when it comes to their ability to make the best decisions for their loved ones and themselves as caregivers, according to AFA.

The data show that African American and Hispanic caregivers are more likely than caregivers of other races to regard the disease as a normal part of the aging process. In addition, 67 percent of African Americans and 63 percent of Hispanic caregivers were "significantly more likely" to report that they did not know enough about the disease to recognize the symptoms, compared with nearly 50 percent of caregivers of other races.

Additional findings reveal that when it comes to treatment of Alzheimer's, a majority (67 percent) were not currently aware of the concept of combination therapy. "Combination therapy describes treatment combining medication from the two classes of Alzheimer's disease drugs currently approved" by the Food and Drug Administration, according to AFA.

Other factors, such as a stigma associated with the disease, religion, and spirituality, also played a role in the delay of diagnosis of Alzheimer's.

"Facing Alzheimer's disease is never easy, but getting a diagnosis and taking advantage of support services are crucial steps to treating and managing the disease," said Eric Hall, chief executive officer of the foundation. "We encourage everyone touched by Alzheimer's disease to reach out for assistance—help is out there."

—**Meg LaPorte**