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Understanding the Challenges for Hospice: Fundamental for the Future

by Joy Stair, M.S., B.S.N.

Hospice care traditionally has been acknowledged as a component of oncology care, regardless of its degree of integration or type of relationship with an oncology service line. The most common model is one of collaboration with a free-standing hospice that contracts with hospital-based oncology programs for inpatient beds. As is the case in all care settings, the financial and customer-focused pressures of today's health care environment are challenging the American hospice to determine ways to preserve hospice's essential values of compassion and commitment to the real needs of dying patients. Hospice's current and potential allies and partners must understand the day-to-day realities if they are to encourage the preservation of hospice's core goals and values.

As an interdisciplinary team-based care model guided by a single plan of care, hospice is already functioning in a managed care mode.[1] Under the current per diem payment methodology of Medicare and Medicaid, hospice has more than a decade of experience in sharing financial risk with payers.

A primary concern that hospices face is the realization that reimbursement will not continue to rise at the current rate, and may even fall. More than half the nation's hospices—including the vast majority of rural hospices—had their per diem payments reduced, effective October 1, 1997, under a new hospice wage index. An analysis by the National Hospice Organization estimates about 53 percent of hospices will be affected negatively—and that is just in the first year of a two-year phase-in of cuts.[2] The wage index will be updated each year, according to the Health Care Financing Administration (HCFA). Another concern is that as competition increases among the various health care networks and community health care systems, it is probable that increasing numbers of hospices will merge, creating larger programs. This process will most likely develop in communities where there are large numbers of hospice programs relative to the population. Such consolidation could prove painful to those hospices with long histories of community involvement and support.

The Clinton Administration's initiatives to curb Medicare and Medicaid fraud, waste, and abuse have had particular implications for hospice care.[3] Based on preliminary information, the provisions specific to hospice make considerable changes in current benefits and operations. Under this plan, for example, physicians who *falsely* certify the need for hospice services are subject to new civil money penalties, which means the physician must accurately identify "terminal" patients, i.e., those with a life span of six months or less. Although this may be more obvious for patients with cancer diagnoses, other eligible beneficiaries (e.g., those with Stage III and IV congestive heart failure) may not be as easily categorized. The end result is that patients are being referred to hospice programs at extremely late stages when death is clearly imminent. The average hospice length of stay is, therefore, declining dramatically and has the following negative impacts:

- The patient and family do not receive the full benefits of the hospice program services, which focus on palliation and relief of suffering, enhancing individual control and autonomy at the end of life, and the value of healing or maintaining meaning and personal integrity in the dying process.
- While the emphasis of today's health care involves placing the patient in the most appropriate and cost-effective setting to meet his or her needs, patients are often maintained in a more expensive, acute care model.
- The financial impact on hospice is negative, because the per diem reimbursement does not begin to cover the intense resources required over a shortened length-of-stay at the very end of life.

The caseload served by hospices has changed considerably from the movement's origins in suburban communities and largely white, middle-class, stable family populations.[4] Ethnic minorities, marginalized persons, and those without stable home environments or living in nontraditional ways are not well served by hospice at the present time.[5] Leading hospice managers increasingly notice that many of their "customers" or potential customers are intimidated by or unreceptive to the hospice concept as they perceive it. Such inhibitions are stimulating the development of pre-hospice or "bridge" programs for those who, regardless of the clinical evidence, are unwilling or unable to acknowledge the possibility that their illness might be terminal. Others have developed

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new models, definitions, and service packages to care for people with HIV disease or Alzheimer's.

ADDRESSING THE CHALLENGES

Managed care's commitment to remove waste from health expenditures will continue to put pressures on hospices, particularly if managed care contracts are awarded primarily on the basis of price discounts. A related problem is how to make payers understand (and cover) hospice's interdisciplinary, all-inclusive, mini-managed care approach to coordinating the services required by terminally ill patients.

The development of integrated health delivery systems challenges hospices to understand these new networks and claim a niche in them; it makes no sense for hospices to remain isolated from these comprehensive systems as they assemble integrated, cradle-to-grave continuums of health care for covered populations.

Beresford[6] raises the following questions to consider in terms of preserving hospice values in the face of change:

- How will standards of quality hospice care be defined, and who will enforce them? What are the objective yardsticks to differentiate quality hospice providers, regardless of tax status, from profiteers?
- What are the quantifiable outcomes measures in hospice, given that the mortality rate is nearly 100 percent?
- What are the core values, goals, and guiding mission of hospice? Can the movement articulate and communicate its bedrock goals as many of its traditional trappings and structures fall away under health care reform?
- Are there effective new methods of defining and pricing hospice's package of services, for example, under capitation?
- Who will provide hospice care? Who will be hospice's health care partners? Where does hospice care fit into integrated delivery systems?

The answers to these questions are crucial to both hospice and the oncology product line for a number of reasons. Consider that an estimated 1.2 million Americans will be diagnosed with cancer this year. Despite significant strides in early detection for certain malig-

Medicare and Hospice

The Hospice Medicare Benefit* covers all patient care services that are reasonable and necessary for the palliation and management of the terminal illness. Under this definition the following services are mandated:

Levels of Care

- Home care
- Inpatient care for acute problems
- Continuous care, defined as eight or more hours per day of care provided by an RN or LPN to the patient at home for periods of crisis (when additional intervention in the home may prevent the patient's hospitalization)
- Respite care

Professional Services

- Nursing
- Social Worker
- Chaplain
- Medical Director
- Bereavement Staff
- Therapists (OT, PT, Speech, Dietary Counseling)

Laboratory Services

All laboratory services "essential" for a treatment or recertification decision, or aimed at controlling a symptom related to the terminal illness

Medications

Effective prescription and nonprescription medications are provided to palliate symptoms related to the terminal illness

Medical Equipment

Equipment made available must meet the safety and comfort needs of the patient and ease the care giver's burden of caring for the patient

Oxygen

Medical Supplies

All supplies and equipment that will best alleviate or prevent distressing symptoms are made available to the patient (examples include medically indicated nutritional supplements consistent with care plan, dressings and wound care products, and anti-pressure devices).

Home Health Aide/Homemaker Services

The frequency and intensity of home health aide services is based upon patients' activities of daily living, functional status, adequacy of care giver, complexity of personal care needs, and consistency with the plan of care.

Bereavement Program

A planned bereavement program, which includes at a minimum, short-term individual counseling, support groups, telephone follow-up and written information; family follow-up at regular intervals for at least one year after the patient's death.

Spiritual Care

Spiritual assessment and periodic offers of spiritual services consistent with the patient's beliefs

Volunteer Program

Sufficient number of trained volunteers to offer and deliver services to assist patients and families

Ambulance

Any ambulance or other patient transport that is medically indicated by the terminal illness is authorized by hospice consistent with the plan of care

Other

- IV therapy needed for symptom management
- Palliative radiation and chemotherapy

* The National Hospice Organization. Hospice services guidelines and definitions. *Hospice Journal* 11(2):65-73, 1996.

nancies and continuing advances in cancer treatment, nearly half will die from their disease, often with the pain, discomfort, and psychosocial distress that hospice care is designed to relieve. Furthermore, oncology has been in the forefront of establishing and supporting holistic care for patients and families across the continuum; hospice is fundamental to this concept.

DEVELOPING A PALLIATIVE CARE STRATEGY

Although there are a myriad of collaborative efforts and projects that can be undertaken by oncology programs and hospice, five are key at the present time:

- Oncology programs must clearly define their approach to and guidelines for care of patients for whom further cure-oriented treatment will be of no benefit. Although program leadership often believes this to be in place, it is not uncommon for patients and families to pressure physicians to offer a second-, third-, and even fourth-line therapy and to "do everything possible." As resource utilization becomes even more of an issue in the future, a clearly articulated approach will help both care givers and patients understand the timing and benefits of a palliative care strategy. It will also be useful in negotiations with third-party payers.
- Guidelines and procedures for transitioning patients to a palliative care model should be developed collaboratively by oncology and hospice programs. Currently hospice and home care programs are effectively developing methods to transition patients from home care to hospice through such activities as case sharing between the home care and hospice RNs and utilizing the hospice social worker to see home care patients who will become hospice patients. Hospice leadership can be of great assistance in helping oncology care givers understand the benefits of hospice to the patient; hospice staff are willing to make informational visits to patients and families to assess readiness and begin a working relationship.
- A basic in-service program on the Medicare hospice benefit for oncology staff is important so that cancer care providers understand the advantages for patients and families eligible for hospice. Although most oncology professionals are familiar with the hospice concept, many are unaware of the fact that included in the hospice benefit are such things as all pain medications, oxygen, and home medical equipment.
- Oncology programs should initiate discussions with hospice to understand cost and reimbursement issues. This will better position the cancer program for a move to capitation.
- If hospice is not formally a component of an integrated delivery system, develop criteria to evaluate potential partners in the future, including quality and financial effectiveness. Although hospice care is reimbursed on a per diem basis, many hospices have been more successful at developing a quality product than streamlining costs and effectively utilizing resources. The historical hospice approach has been to provide everything for the dying patient rather than clearly assessing needs. Hospice has often been subsidized through philanthropic efforts, making such efforts possible. It is questionable, however, with increasing competition for philanthropic dollars, whether previous levels of fundraising will continue in the future.

The health care environment is changing at a pace that few could have predicted. Hospice care is very much part of that change. Despite the challenges, partnerships among hospices, delivery networks, and managed care companies will be critical to the continued expansion of access to hospice care and to ensure the availability of hospice to those in need. Oncology's interest in and support of the future of hospice should be a foremost goal. ■

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Hospice and Hospital

The introduction of the Medicare hospice benefit in the late 1970s and early 1980s brought the issue of fixed reimbursement to hospice, a segment of health care that had little previous experience in monitoring its costs. Hospice after all had been founded on the principle of providing quality care to terminal patients, and cost issues had often come secondarily to patient comfort.

Since the 1980s, however, hospice has adapted well to the marriage of quality and cost, providing quality care for patients at approximately $100 a day.[1] Studies continue to show that hospice is the most appropriate and cost-effective way to care for terminally ill patients.[2]

Nevertheless, further changes loom ahead. Declining reimbursement from Medicare and Medicaid continues to be a threat. Increasingly third-party payers are demanding more sophisticated outcomes data to justify expense. More than ever hospice must balance the precarious balance of satisfying patients' needs with its own financial viability.

For many hospice organizations, integration with a hospital's palliative care program provides the structure to facilitate more cost-effective care. At the Cleveland Clinic Hospice, part of the Palliative Medicine Program at the Cleveland Clinic Foundation in Cleveland, Ohio, hospice is one component of a comprehensive palliative care strategy that ensures patient access to appropriate palliative intervention from initial diagnosis to, if necessary, terminal illness. The Palliative Medicine Program supports hospice through research studies, development of standards of care, professional and staff education—all of which contribute to better patient care and a healthy bottom line.

A PALLIATIVE CARE STRATEGY

The Cleveland Clinic Foundation's Palliative Medicine Program was founded in 1987 to provide symptom management and psy-

chosocial support to patients with advanced cancer. The Palliative Medicine Program is based within the Harry R. Horvitz Center, a twenty-three bed acute inpatient care unit dedicated to pain and symptom management. Palliative care staff include one medical director, two attending physicians, three clinical fellows, three nurse clinicians, one full-time social worker, two music therapists, and a dedicated hospice home care staff.

The Palliative Home Care Service, the program's precursor to hospice care, is for those patients who may not be emotionally ready for or ineligible for hospice. In addition, the Palliative Care Consult Service is comprised of a dedicated palliative care attending physician, clinical fellow, and nurse clinician, who evaluate referrals and facilitate patient access to the Cleveland Clinic's palliative care programs. This consult service is available to inpatients and outpatients from the time of a patient's initial diagnosis.

The Hospice Home Care Service is one in a series of steps to ensure that cancer patients receive palliative treatment when and where appropriate, stated Pamela Goldstein, R.N., B.S.N., M.P.A., director of the Cleveland Clinic Foundation's Hospice Homecare Service. The home-based hospice program enrolls those patients for whom treatment therapy is no longer an option, providing comprehensive symptom management and pain control to achieve patient comfort. The hospice's close link to the Palliative Medicine Program ensures the day-to-day involvement of medical oncologists specialized in palliative care.

Patients with recurring symptoms may be transferred to the Horvitz Center for short-term treatment and are transitioned back to the home as soon as possible. Such ready access to the Horvitz Center may mean that patients re-enter the system as inpatients more often. However, once there, patients' stays are minimized, which, Goldstein said, results in better care in the long run. "We have the ability to monitor complications related to advanced disease, such as new or exacerbated pain, spinal cord compression, or pleural effusion; seek the advice of palliative care trained physicians; intervene before the problem hits a crisis level; and have the patient back home, said Goldstein. Without such ready access to palliative care specialists, Goldstein believes such complications would likely go untreated.

EDUCATION AND STANDARDS

The Palliative Care Consult Service plays a significant role in educating physicians from all specialties and their patients about the importance of palliative care throughout the treatment plan. This effort is an attempt to circumvent the larger trend in this country of physicians wanting to (and some patients or loved ones asking them to) aggressively treat cancer just weeks prior to death at the expense of a patient's quality of life. Too often, Goldstein said, hospice is viewed by physicians as a luxury for patients when the timing is right. However, by introducing physicians to the number of palliative care options available from the beginning of a patient's treatment, "we can teach physicians that palliative care does not necessarily begin in hospice two weeks prior to death," said Goldstein. The goal, she said, is for physicians to view hospice as another piece of a patient's treatment plan.

In addition to informal interaction, more formal professional palliative education occurs through workshops, seminars, and conferences. Physicians from all specialties are also encouraged to participate in grand rounds or any of the medical training rotations or fellowship programs.

The Palliative Medicine Program supports a full-time research fellow to spearhead research studies on the effectiveness of palliative and hospice care at the Cleveland Clinic. Best management practices of the most common cancers seen in hospice are studied and then directly applied to patient care.

Goldstein advises hospice programs to develop outcomes measures consistent with its specific population. "Studying mortality rates won't tell us how to more appropriately treat hospice patients," she stated. Setting realistic objectives for measuring outcomes such as patient comfort and level of pain at end of life will help programs streamline and ultimately standardize end-of-life care.

According to Goldstein, standardization should occur on all levels of hospice care, including:

Treatment. Protocols need to be devised and implemented to ensure that pain and other symptoms are treated consistently and logically. Each member of the multidisciplinary team participates in the development of protocols, including nursing care tracks, standing orders, and standardized documentation tools.

Criteria for admission and continuance in hospice. The Palliative Care medical team works with referring physicians in evaluating patients' admission to hospice. All hospice patients are reevaluated on a monthly basis to determine the appropriateness of their care setting. Recertification standards and forms are developed in conjunction with National Hospice Organization guidelines.

Communication and documentation procedures. Field staff are equipped with laptop computers to reduce paperwork and streamline reporting.

For the sake of its patients, hospice can no longer afford to exist in isolation from the hospital. Integration with a comprehensive palliative care program enables hospice to treat patients earlier, thus permitting intervention that is administered more appropriately and more effectively.

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