



The development of a palliative care program

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■ Palliative care, which neither hastens death nor prolongs life, provides comfort through the final stages of life. The focus is on comfort for the patient and quality of life for both patient and family. A three-month pilot project used the team approach, involving a physician, nurse, and social worker, to assess how the palliative care needs of the terminal cancer patient were being met at the Cleveland Clinic. Data are presented to demonstrate that such needs exist and are not currently being met by existing services, as perceived by the patient population surveyed. During the pilot project, the palliative care team was in compliance with the Joint Commission on Accreditation of Hospitals hospice standards.

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CANCER FACILITIES traditionally focus on diagnosis and treatment with chemotherapy, radiotherapy, and surgery. However, traditional treatments may eventually be inappropriate for up to half of all cancer patients. Those unresponsive to such therapy often are not given optimum care and support by health care providers.

Services provided in a palliative care/hospice program have not been addressed at the Cleveland Clinic until recently. Such a program, although not preferred for some patients, should be available for the terminally ill and their families who wish to focus care on comfort and quality of life.

The Cleveland Clinic is characterized by its size, specialization of the staff, traditional focus on diagnosis and treatment, and the large area from which referrals are received. Annually, patient totals include more than

600,000 office visits and 32,000 hospital admissions, of which 2,200 are new cancer patients. Thus, cancer patients represent the second largest population at the Cleveland Clinic, approximately 17% of all admissions (5,440) and 8% of outpatient visits (48,000). In 1985, the Cleveland Clinic Cancer Center was developed to coordinate services provided for Cleveland Clinic cancer patients. Included in the spectrum of cancer care were psychosocial support and continuing care as given by a palliative care/hospice program.

MATERIALS

We conducted a three-month pilot project to assess the palliative care needs of the terminally ill. The patients of three physicians involved in either urologic or medical oncology (Drs. James Montie, J. Edson Pontes, and James Weick) met the following eligibility criteria:

1. The patient and family had to be aware of the palliative care philosophy and agree to participate in the service.
2. The diagnosis must have indicated that the expected remaining lifespan would be six months or less. The diagnosis was not limited to cancer and included

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those who had not responded to traditional curative therapies.

3. The patient and family had to be aware of the diagnosis and expected lifespan.

4. All traditional curative therapy must have been attempted, and the goal of therapy was palliation.

5. No patient was to be denied service on the basis of age, sex, color, religion, national origin, or financial status.

An interdisciplinary team (physician, nurse, social worker, and chaplain) was used during the pilot project to plan, provide, and coordinate for both the patient and family. This differed from traditional care. Continuity and quality care were provided by the team in whatever setting the patient was found. Care needs were determined for hospital stays and provided after hospital discharge until the patient's death.

The goals, objectives, and criteria for admission to the program were those established by the Joint Commission on Accreditation of Hospitals (JCAH) and amended by the Palliative Care Task Force of the Cleveland Clinic.

Palliative care philosophy

The focus of palliative care is on life-affirming activities, thus enabling each person to live as fully as possible until death. When curative therapy has been tried extensively and further aggressive treatment is not expected to prolong survival, the patient and family are best served by supportive palliative care.

Goals of palliative care

Palliative care provides symptomatic relief, medical consultation, and skilled nursing, which enable the patient to remain as alert, active, and comfortable as possible. It also provides the patient and family with psychological, social, and spiritual support throughout the illness and continues this support for the family after the patient's death. Finally, palliative care supplements and assists, but does not duplicate, existing health-care assistance.

Palliative care objectives

Services of various health-care professionals are coordinated to provide an interdisciplinary team approach to the care of the terminally ill and their families while the patient is in the hospital and after the patient is discharged. Policies and procedures are developed to maintain this coordination. The team is also an educational resource for hospital personnel, patients, their families, and the community. These services are assessed

and evaluated periodically to improve the quality of care.

METHODS

Twenty-four patients were referred from the three physicians to the palliative care team for consultation. Other staff members of the Department of Hematology and Medical Oncology identified an additional 107 patients for palliative care during the three-month period. These patients were not included in the pilot project, however, because they were not referred by the three participating physicians. Yet from this information, we estimated that 516 patients per year (43 referrals per month) from the Department of Hematology and Medical Oncology alone would use the palliative care program.

RESULTS

Palliative care needs

Data required to complete the project included the assessment of patient demographics, pain, functional abilities, financial resources, and emotional needs, according to JCAH standards.

Demographic assessment. Of the 24 patients surveyed (age range, 42.5–78.3 years; mean, 59.9 years), 16 were women, 18 were currently married, 17 had someone in the home to assist with care, and 20 lived within a 30-mile (48-km) radius of Cleveland. Ten were estimated to have a life expectancy of one month or less.

Pain assessment. Fourteen patients complained of pain. Frequently used medications at the time of initial consultation were oxycodone, hydromorphone, and morphine sulfate.

Functional assessment. Patients exhibited a wide range of physical abilities, and many indicated that walking, propelling a wheelchair, and managing stairs were the activities most difficult to perform. Five patients were totally dependent, and four were totally independent. Medical supplies in highest demand were hospital beds, Foley catheters, and Chux underpads.

Financial assessment. All patients surveyed for the pilot project had some form of insurance coverage. Nine were Medicare beneficiaries, and 15 had coverage from other insurance carriers.

Emotional assessment. The emotional assessment dealt with areas of loss, patient feelings (ie, anger, guilt, fear, and anxiety), and communication patterns. Results indicated that 22 patients believed that their death would result in the disruption of the home setting of the

TABLE 1
INFORMATION PERTAINING TO 24 PATIENTS UNDERGOING
PALLIATIVE CARE

| | Mean | SD | Range |
|--|------|-------|-----------|
| Age (years) | 59.9 | 10.14 | 42.5–78.3 |
| Length of stay (days) | 14.9 | 7.29 | 3–27 |
| Time to consultation (days) | 6.6 | 5.21 | 1–21 |
| Time from consultation to discharge (days) | 7.4 | 4.95 | 1–14 |

surviving spouse/caregiver. Eleven were reluctant to face the facts of their illness. Additionally, there was a wide range of intensity of emotion. Some patients, however, indicated that they did not feel anger (1), guilt (20), anxiety (14), or fear (10).

Standards of care

The standards identified by the JCAH for hospice care were evaluated before consultation and again at hospital discharge.

Patient/family unit of care and interdisciplinary team services. Prior to direct involvement by the Palliative Care Team, only one-third of all patients and families had been under a written care plan developed by social services. Of those under such plans, only 4% had plans that included the needs of the family and identified a psychosocial need. At the initial interview, 22 of the 24 patients reported that they had had a discussion with their family and social-services personnel concerning alternative care. By the time of discharge, all reported they had had such a discussion. Additionally, when asked at the initial interview and at discharge, all patients claimed that a nurse was available to answer their questions or those of their family. Upon discharge, all patients had undergone counselling by social workers and a written care plan identifying patient and family needs had been formulated.

Continuity of care. All aspects of hospital care, continuity of care upon admission, transfer, and social service needs were attended to by the Palliative Care Team. During the pilot project, six persons used occupational and physical therapy. All team members assessed patients within 24 hours of time of referral, and

care plans were formulated. Specific information regarding discharge and/or transfer needs was not available from hospital documentation; this was documented by the team in the progress notes. Referrals for consultation were made to home-care agencies for 17 patients. Nineteen of the 24 died in the hospital.

Inpatient services. JCAH standards state that accommodations be available so family members can remain with the patient throughout the night. This standard was met for only two patients.

Length of stay. Table 1 describes length of stay. The average was nearly 15 days. Usually, a palliative care consultation was requested seven days after admission and seven days before discharge. Delays in requesting consultation frequently occurred due to medical evaluations for the desirability of continued "curative" forms of therapy.

DISCUSSION

Traditionally, the focus of a hospice program is humanistic, based on the concern for the "well-being of the patient and family."¹ Although standards of care for such programs have been developed by the JCAH, limited research is being done in the areas of symptom management, pain control, and assessing the basic needs of patients and their families.²⁻⁴ The pilot project demonstrated that a need exists at the Cleveland Clinic for a more systematic, reliable, high-quality program for the terminally ill patient and family. Such a program was needed for both the hospital and home setting.

As more quality programs are developed and research is done, establishment of recognized techniques and standards of care can be initiated. The Cleveland Clinic has developed a palliative care program in accordance with the JCAH standards consisting of a consultation service and will plan to institute an inpatient hospital unit and a home-care component in the near future.

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