

A Homecare Hospice Profile: Description, Evaluation, and Cost Analysis

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After analyzing its first year of operation, a homecare hospice staff describes its patient statistics (n=70), its evaluations received from the patients' families, its inability to accept many referrals (n=150), and its cost analysis. The mean patient longevity in the program was 42 days for a cost of \$65 per patient day. The patients' families reported they were more than 90 percent satisfied with services rendered, although their level of satisfaction with their physicians was lowest (75 percent). Many referrals were not accepted into the caseload because contact came so late that the patient died before processing could be completed. The data indicate that the hospice program was urgently sought by the public and that the hospice reported in this study will be able to provide homecare services at a cost which is competitive with skilled nursing home care.

Many homecare hospices have appeared in the United States in the last ten years,^{1,2} but only Hospice, Incorporated, of New Haven, Connecticut, has statistically described its results in the literature.³ Most hospice literature is a discussion of principles rather than facts and results. The American hospice program suffers from this lack of statistical data and analysis of results. Callan has noted that the medical establishment has not been able to determine whether hospices can be a

viable part of the American health care system.⁴ Hospices do not deserve a place in the system unless they can demonstrate competent and efficient results. Potter has pointed out that blind acclaim for hospice objectives without appraisal of results is an invitation for abuse.⁵ Abuse can be identified and curbed only after existing hospices report concrete data that elucidate the hospice principles and set standards.

Responding to this need, the staff of the Hospice of Columbus (HOC) in Columbus, Ohio, has analyzed their first year of operation in terms of description of cases, evaluation results from families who used services, and cost analysis. When a referral was not accepted, the staff catalogued the reason. These data were intended for internal program refinement and for scrutiny by the health care community. This article reports this experience.

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The Program

In 1979 HOC, having a Board of Trustees, was incorporated as a nonprofit independent cancer hospice. It was not a certified home health agency. Initial funding was received from local foundations and interested citizens. Personnel included an oncologist who served part-time as medical director, an executive director, three full-time nurses who were placed in HOC by the city and county health departments, a half-time nurse, a homecare nursing supervisor, a half-time social worker, a coordinator of education and volunteers, and an administrative assistant. Most of the nurses had baccalaureate degrees and experience in community health care or oncology nursing. Services to the patient included 24-hour availability of a nurse through an on-call system.

To be accepted into the caseload of HOC, the cancer patient needed the support of a physician who would assume responsibility for hospice medical and nursing management in the home. It was necessary that the patient be at least 18 years old and live in Franklin County, the metropolitan area of Columbus. An estimated longevity of 48 hours to six months was required. Both the patient and family needed to be informed of the diagnosis as well as the prognosis and to be in agreement with the principle of providing only palliative care. The patient and family needed to designate at least one person as "care giver," one who would be the primary link with the hospice staff and assume responsibility for the daily care of the patient.

The program was organized along the following familiar principles of hospice⁶:

1. The primary unit of hospice care is the patient and family.
2. Hospice provides physician directed interdisciplinary care.
3. Hospice services are available on-call at night, on weekends, and holidays.
4. Hospice is committed to symptom control.
5. Hospice trains volunteers to aid and support the patient and family.
6. Hospice provides bereavement follow-up to the care giver and family.
7. The hospice organization provides time and structure for staff support.

During its first year, HOC cared for 70 patients. At the end of the year of service, an evaluation form requesting an anonymous response was

mailed to the care givers. A follow-up phone call requesting a response was made after three weeks. Many could not be reached. All care givers who were contacted, however, had responded except a few who requested another form. In all, 45 care givers (64 percent) responded to the questionnaire. The evaluation gathered feedback concerning the level of satisfaction with their physician while the family member was a patient of HOC, with the effectiveness of pain control, with the nursing skills, with the supportiveness of the nurses, with the social worker, and with the volunteers. The care giver responded by placing an X on two undifferentiated 16-mm lines placed under each item, the first designated to reflect the care giver's level of satisfaction and the second to reflect the satisfaction of the family as the care giver understood it. The left end of the line was marked "100 percent dissatisfied"; the right end was marked "100 percent satisfied." An X at the 16-mm point equaled 100 percent satisfied.

Evaluation of One Year's Experience

Patient Demographics

The mean age of the 70 patients was 65 years with a range of 23 years to 89 years. Sixty-seven patients (96 percent) were white and three (4 percent) were black. There were 33 men (47 percent) and 37 women (53 percent).

The mean age demonstrates that this hospice was not an institution caring only for geriatric patients. The request for services from younger patients was pleasing to the staff. The nurses, however, tended to identify with the younger patients, making their work with these patients more difficult.

The racial characteristics of the caseload were not representative of the community because HOC received patients primarily from white referral sources. Hospice, Incorporated, the only other program which has published its results, reported a similar preponderance of white patients.³ Future data analysis from other hospices should seek to determine whether this is a frequent pattern.

Demographics of Care Giver and Household

The role of care giver was filled by the spouse in 53 percent of the families, an adult child in 33 percent, and some other relative or nonfamily member in 14 percent. The mean age for these care givers was 52 years, 13 years younger than their patients.

Frequently family members other than the patient and care giver lived in the home. When these additional family members were adults (48 adults in 32 percent of the families), they created more complex family relationships but were often helpful in meeting the many demands on the care giver. When these additional family members were children (36 children in 31 percent of the families), they created more stress in the household. In these families hospice nurses worked in especially complex family dynamics. Consultant psychotherapists provided inservice education and case discussion time so that the nurses could become more effective in dealing with the family members' intense, sometimes conflicting feelings.

Patient Longevity

Patient longevity data reflects the rapidity of patient flow through hospice. The rate of flow dictated how long new patients waited before admission to an already full caseload and how often nurses needed to go through a grief experience with a family. The mean length of time on the caseload was 42 days; the range was 1 day to 387 days. Hospice, Incorporated, reported a mean of 70.5 days with a range of 1 to 630 days. The difference warranted exploration because it was substantial. Hospice, Incorporated, suggested that its length of stay was inflated by those who outlived their original prognosis, who undertook further curative treatment, or who went into unexpected remission. They kept these patients in the program to provide a stable baseline population.³ Apparently, Hospice, Incorporated, accepted patients who had terminal disease but who had not deteriorated into the final terminal process, thus extending the organization's mean patient longevity. Hospice of Columbus estimated the remaining life span and accepted patients according to its criteria that lon-

gevity be less than six months, thus keeping its mean longevity shorter.

Referral Routes

Twenty-three patients (33 percent) were referred by themselves or their families. These families contacted HOC and took initiative with their physician. In contrast, 16 patients (23 percent) were referred by the medical oncologist who functioned as the medical director of HOC. The remaining 31 patients were referred by public health nurses, hospital social workers, and other individual physicians.

The 70 patients of HOC were cared for by 43 physicians. In the evaluation of the patient's physicians during the hospice experience, the care givers reported a mean score of 75 percent satisfaction. They reported a mean score of 78 percent satisfaction for their families. These results were the lowest received in the entire evaluation. Perhaps experience with HOC will aid the physicians in providing more satisfactory relationships.

Diagnosis and Medical Care

The most frequent diagnoses were lung cancer (15 or 21 percent) and breast cancer (10 or 14 percent). Before coming to hospice, 62 patients had radiation, chemotherapy, or surgery. Only eight patients had had no treatment before admission. These findings supported the staff's opinion that patients had used treatment fully before turning to hospice. Conversely, the findings did not support critics who believed that hospice patients tend to ignore the benefit of treatment.

Patients sometimes required hospitalization. HOC had no inpatient facility, and thus the physicians admitted the patients to community hospitals. Sixteen patients (23 percent) were admitted once and two (3 percent) were admitted twice. The necessity for better symptom management accounted for the admission of 11 patients, rest for the care giver necessitated the admission of three patients, and both of these reasons forced the admission of four patients.

Hospice Nursing Care

The average number of nursing visits made to patients' homes was 13, although one patient required 176 visits. The average length of a nursing visit was 95 minutes; consequently, the mean contact time with the patient during 42 days in the program was 20.5 hours.

Countywide travel for patient home visits consumed time and thus necessitated study. Nurses estimated round-trip travel time from office to home and multiplied this by the number of visits. Nurses' round-trip travel time per visit was 63 minutes. This travel time was an accurate estimate, although the nurses frequently made two or more visits per trip out of the office. A home visit with its travel time therefore consumed approximately 2.5 hours (158 minutes) and a patient with a mean of 13 home visits during 42 days consumed approximately 34 hours. In the evaluation, the care givers reported that they and their families were 93 percent satisfied with nursing care and the supportiveness of the nurses.

Sometimes telephone calls were a time saving substitute for personal contact. This made telephone usage important, particularly in providing patient management and in obtaining medical supervision. The nurses placed 537 calls to patient homes. The mean was 8 calls per family, although one family was called 39 times. Conversely, families called HOC 299 times. Nine families never called for help during regular working hours, but one family placed 22 calls.

Also, the patient's physician supervised hospice homecare by telephone. The nurses placed 512 calls to the patients' physicians to obtain medical supervision. Many of these calls were made to adjust analgesics.

Interdisciplinary Care

Patients also required care from professionals in other disciplines. A social worker became part of the staff and was active in the intake screening process and in assisting families in their various applications for financial aid. In the evaluation, care givers reported that they and their families were 91 percent satisfied with the social worker.

A pharmacist, a psychologist, a nutritionist, and a family therapist who was also a minister provided volunteer time. They offered consultation, joined

the staff for home visits, and provided contacts with other community support systems. All participated with the staff in a weekly case conference.

On-Call Services

On-call services required that a nurse remain available by phone and make home visits as needed. Providing these services was exhausting to the staff, even though volunteer nurses worked one third of the scheduled times. Phone calls at night and on weekends totaled 308, resulting in a mean of 4.4 calls per family during the 42 days in the program. Some families tended to use on-call, whereas others did not. When these data were refined, they revealed that eight families (11 percent) never used the service and that ten families (14 percent) used the service ten or more times.

Thirty-one calls (10 percent) were made to inform the nurse that the patient had died, and 95 calls (31 percent) were made to ask for reassurance. Another 182 calls (59 percent) were made to request help with medical and nursing needs.

In addition, on-call work required home visits. The 308 calls reported above resulted in 97 visits. Thirty-one visits (32 percent) were made to pronounce the patient dead, while 14 (14 percent) were made to give reassurance, and 52 (54 percent) were to provide medical and nursing help. These visits were made for 50 families (71 percent of all families on the caseload). Most families required only a single visit, but one required nine.

The on-call services of HOC were more heavily used than the call schedule of a family practice group. Curtis presented data which established call frequency at 4.89 calls per 10 patients per year.⁷ An analysis of HOC data, however, documented a frequency of 44 calls per 10 patients per year. He also reported that 70 percent of the calls to physicians were managed on the phone and required no other action on their part. A review of HOC statistics, however, indicated that although 69 percent of the calls needed no further action, the remaining 31 percent required a home visit.

Symptom Control

A volunteer pharmacist who specialized in pain problems was helpful in symptom control. The pain medications used most frequently were mor-

phine (22 patients) and levorphanol (19 patients). The remaining group of patients required less powerful analgesics, except for seven patients who required no pain medication at all. The care givers were 92 percent satisfied with the effect of these medications. They reported that their families were 91 percent satisfied.

Role of Volunteers

A staff member of Hospice of Columbus was appointed coordinator of education and volunteers. She screened volunteer applicants and constructed a training program. The nurse regularly assessed the family's need for a volunteer. A volunteer was requested and assigned to 29 families (41 percent). Families were 92 percent satisfied with the contribution of the volunteers. No doubt, supportive volunteers helped the family to endure this prolonged period of stress.

Bereavement Follow-Up

The hospice team provided bereavement follow-up for one year. By HOC policy, the nurse initiated one visit with the care giver after attending the funeral. Subsequent contacts were then negotiated or left in the hands of the care giver. Each family was invited to the bimonthly supper sponsored by HOC. These suppers provided an opportunity for families to meet each other and find support in new relationships. A brief note was sent to the care giver at the first anniversary of the death.

Staff Support

A biweekly staff support group was part of the program from the beginning. A volunteer consultant from outside the organization led the group. During the nonagenda 90-minute period, the staff discussed professional concerns. Although these sessions were expensive because all staff members were taken away from their work, the meetings were efficient because reduced stress led to increased effectiveness. Administrative and clinical staff members believed the group meetings were critical.

Patients and Families Not Accepted for Care

Hospice of Columbus did not accept into the caseload 150 of the patients who were referred. The major reason was that patients died before evaluation was completed (11 or 26 percent). In 26 cases (17 percent) families or physicians made initial contact but did not follow up. In 24 cases (16 percent) no one was available to fill the role of care giver. In 17 cases (11.3 percent) the referral was premature by HOC criteria because the patient was still involved in curative treatment. The 42 remaining cases (28 percent) were not accepted because they did not meet one or more of the remaining previously outlined HOC criteria.

As in every service organization, the profile of HOC was built not only by the patients it served but also by the patients it could not serve. HOC focused on well-planned and consistent relationships that sustained the patient and family. Many patients did not receive service because the referral came too late to achieve these goals. Usually these patients were under the care of other home-care agencies or were in the hospital; when the death of the patient seemed imminent, the family rushed to HOC for help. These patients were not accepted because making arrangements for terminal care in the home was more difficult and time consuming than these families realized. Additionally, HOC resisted the temptation to become an emergency home care agency. This policy produced the mean patient longevity of 42 days. Other hospices will produce variant data depending upon how they respond to these pressures from the public.

Cost of Care

The cost described here includes the salaries of three full-time nurses placed by the city and county health departments, although HOC did not actually pay their salaries. A statement concerning HOC income is impossible because HOC generated no patient care money for itself. To recover their costs, the city and county health departments billed insurance companies for the services of their three nurses. Other hospice services, such as social service visits, bereavement follow-up, spiritual care, and family counseling, were generally not

reimbursable. The board of trustees, therefore, simply did not undertake to collect any fees. Predictably, this placed HOC in a difficult position as seed monies ran out. At the end of the first year a financial crisis was resolved by placing HOC within the city health department.

Cost of care analyses, therefore, examine only the expenditure of funds and an estimation of what HOC services would have cost the patients if they had been billed. These charges are compared to nursing home and hospital care, the alternative to hospice available to the public. The analysis is done in three levels so that the total expenditures can be broken down into staff salaries, a fundamental cost of any hospice. First, the total budget for the year was calculated and analyzed to present a global picture. The second level of analysis peels away all expenditures except staff salary costs. Third, staff salaries are broken down to reflect the costs of nursing staff and administrative staff.

The total budget for the first year was approximately \$190,650, or \$522 per day. If these costs had been distributed among the patients for payment, a charge for patient care per day would have been made. The total patient care days generated by HOC during the year was 2,940 (70 patients multiplied by the mean longevity of 42 days). When this total was distributed among 365 days, the result was 8.05 patient care days per day. If each of these patients had shared in the daily cost, the charge would have been \$65 per day, for a total of \$2,730 for the 42-day average enrollment.

At the second level of analysis, only staff salaries were included. The salary budget was approximately \$133,300, or \$365 per day. Paying for staff salaries would have cost patients \$45 per day in the program, totaling \$1,890 for the average of 42 days.

At the third level, the staff salaries were divided into costs for nursing and administrative staffs. Staff salaries for the nurses, including the home care nursing supervisor, were approximately \$74,000, or \$203 per day. The cost of nursing personnel would have cost the patient \$25 per day, totaling \$1,050 for the average of 42 days. Staff salaries for hospice administration was \$59,300, or \$162 per day. This would have cost the patient \$20 per day, totaling \$840 for the average of 42 days.

These costs were examined in relation to those of hospital or nursing home care. The charge for

hospital care in the community averaged \$126 per day (private room), \$5,292 for 42 days. Skilled care at a nursing home averaged \$50 per day (private room), \$2,100 for 42 days. Thus, participation in the HOC program for 42 days would have cost the patient the equivalent of approximately 22 days in the hospital. Of course, physician and medication charges would have been an additional expense in any hospital, nursing home, or hospice. The cost of care from HOC would have been \$15 per day higher than the skilled care purchased from a nursing home. Care from HOC will become competitive with skilled care in a nursing home as HOC becomes more efficient with experience. As the core of trained volunteers to aid the patient and family is strengthened, the services they provide will save staff time and enable even more efficiency and lower costs.

Comment

An eager public often overlooks the complexity of providing hospice home care. This report begins to analyze this complexity and hopefully will encourage other analyses so that hospice can find its place in the American medical establishment.

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