

Evaluation of a Home Based Hospice

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A home based hospice was evaluated by means of questionnaires filled out by surviving relatives of patients who had participated in the hospice program prior to their deaths. Respondents reported that the hospice was helpful in reducing the prevalence of pain, physical disabilities, and anxiety to the dying patient. It was even more helpful in reducing anxiety in relatives of the patient than in the patient himself. Participants approve of the concept of a person dying at home and all would recommend the program to others. Problems in the physician-patient relationship were identified. Although help with bereavement is generally regarded as an integral function of the hospice, respondents in this study reported that it was not an important area with which the hospice needed to concern itself.

The concept and establishment of the hospice is of quite recent onset. The prototype of the modern hospice, St. Christopher's Hospice in London, opened its doors only 12 years ago.¹ Since then, a myriad of hospices have been established in Britain, in North America, and around the globe.

Hospice is a program catering to the needs of the dying and their families. It is an organization composed of various members of the health care profession, whose *raison d'être* is to identify the needs of the dying patient and his/her family and to help ameliorate the process of dying. It is usually centered in a particular hospital or office, though it is as much a philosophy of caring for the dying as an organizational structure.

There are three basic types of hospices with various permutations: (1) the free standing inpatient hospice, exemplified by St. Christopher's; (2)

the hospice unit within a general hospital, exemplified by the Royal Victoria Hospital in Montreal²; and (3) the home based hospice as described in this paper.³

Because of the newness of the hospice and its rapid proliferation, critical evaluation is needed to ascertain if it is performing a valuable function. A large-scale evaluation of a hospice in North America was undertaken by Lack and Buckingham⁴ in studying the New Haven Hospice. Through the use of self-report questionnaires, they concluded that "Hospice patients had lower levels of anxiety, depression, and hostility than did non-Hospice patients." In addition, they found that "Hospice primary care persons had lower levels of anxiety, depression, hostility, and many aspects of social maladjustment than did non-Hospice primary care persons."

The present study sought to add knowledge to this area by evaluating the Fairview Hospice program in Minneapolis. Surviving relatives of patients who had recently died, and who had been involved with the Fairview Program, were contacted and requested to fill out questionnaires regarding their experiences with the hospice program.

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Hospice Program Description

Criteria for admission to the Fairview Hospice Program, a home based hospice program, include:

1. Prognosis of less than six months in a cancer patient.
2. Presence of a "significant other," a relative or friend, who can aid the patient and act as liaison between the hospice and patient.
3. Referral from the patient's physician, who continues to provide care to the patient even while the patient is involved with the hospice.
4. Home located within a 30-mile radius of Fairview Hospital.

Goals of the Fairview Hospice include:

1. To help the dying patient be as alert and symptom free as possible.
2. To include the family in the care of the patient.
3. To care for the patient at home as long as it is within the wishes and ability of the patient and family.
4. To educate the public concerning the principles of hospice care.

The hospice is staffed by two full-time registered nurses; one part-time social worker, occupational therapist, dietician, registered nurse, and chaplain; six volunteers; and physician advisors. The two full-time nurses coordinate the team and the care of each patient. They are available 24 hours per day to do nursing care as well as supportive care in the home. All of the team members can and do make home visits as deemed appropriate by a hospice nurse or by physician request. Visits are made as often as necessary and can vary from weekly or every other week to daily and, at the time of death, even more than once daily.

Hospice team members are often asked to be at the patient's home at the time of death to offer support and direction and to make necessary arrangements such as calling the physician, appropriate relatives and friends, and the funeral director. Most importantly, hospice team members offer support and care to the family members at this time.

The involved team members attend the funeral or reviewal (a letting go time for family and staff). At least one personal bereavement visit is made by a hospice team member two to three weeks after the death. Involvement in a bereavement group for as long as one year after the patient's death is offered.

Since the program was started in March 1978, 93 patients have participated. Of these, 25 are still alive. Length of involvement of the patients in this study prior to their death was less than one month for three patients, from one to three months for 11 patients, and greater than three months for six patients.

Method

Study subjects consisted of the significant others of patients who had participated in the hospice program for greater than two weeks prior to death and who had died between one month and one year prior to the onset of the study. Significant others were generally easily identified. They were the people—relative or friend—closest to the dying person, who tended to them and acted as a liaison between patient and hospice.

Of the 24 subjects who fulfilled the criteria for admission to the study, 20 participated. Of the remaining four, two refused participation and the other two could not be contacted. Of the 20 who participated, 13 were spouses of the deceased; 4, children; 2, mothers; and 1, a girlfriend.

The deceased consisted of 13 males and 7 females ranging in age from 27 to 86 (mean = 59.65) years, all of whom had cancers of various organs. They all received hospice home care and some, in addition, were hospitalized at various times. Of the 20 patients, 10 died in hospital, 7 at home, and 3 in nursing homes.

A letter of introduction to the study was sent to the significant others by the hospice, explaining briefly the nature of the study and indicating that the person would be contacted by the family practice resident conducting the study. Shortly thereafter, the people were contacted by telephone and an appointment was made to deliver the questionnaire. When the questionnaire was delivered, its purposes were briefly explained. The participants were told that (1) the resident was independent and not connected with the hospice program; (2) anonymity if desired would be completely respected; (3) honest answers were preferable to nice answers; and (4) if any questions were upsetting to the subject or did not apply to them, they were simply to skip them. Approximately two days later, the resident picked up the question-

Table 1. Frequency of Symptoms in Hospice Patients and Significant Others (Total N=20)

	No. with Symptoms	No. Who Experienced Relief	% of Total With Symptoms	% With Symptoms Who Experienced Relief
Pain	17	14	85	82
Other Physical Problems	17	15	85	88
Anxiety: Patient	14	9	70	64
Anxiety: Significant Other	19	17	95	89

naires and briefly visited the subjects to ascertain if there were any further comments they wished to make.

The questionnaire consisted of 21 questions concerning various aspects of hospice care. There was room available after each question and an empty page at the end for subjects to add comments.

Results

Several questions were asked concerning the particular problems of the dying patient and the significant other, and if the hospice members and/or physician were able to deal effectively with them. Pain was a significant problem, at least occasionally, to most of the dying patients. Of these, pain was relieved most or all of the time in 82 percent due to the intervention of their physician and/or the hospice. Other physical problems (eg, vomiting, shortness of breath, constipation) were, at least occasionally, major problems for 85 percent of dying patients. Of these, 88 percent gained some relief. Anxiety was identified as a major problem in 70 percent of dying patients and in 95 percent of the significant others. The hospice team helped alleviate symptoms in 64 percent of dying patients and in 89 percent of significant others (Table 1).

When asked about specific religious and/or spiritual concerns of the dying patient, 50 percent of the significant others reported that the patient did not have any special concerns and the rest

were divided between yes, occasionally, and not sure. Fifty-six percent of significant others did not have specific religious and/or spiritual needs at this time. Of those who did, most were able to tap their own resources and did not utilize the hospice. However, three respondents reported deriving great benefit from the hospice chaplain.

Eighty percent of respondents indicated that they derived sufficient information about the patient's illness. The physician was a good source of information in 45 percent of cases and hospice in 60 percent of cases. In only two instances were there other outside valuable sources of information, in both cases physicians in the family.

Interestingly, most subjects viewed the time of the patient's death or shortly thereafter as the most appropriate time to cease contact with the hospice. Only two people felt that the hospice might still be able to help them with major concerns at the present time. Similarly, only four people felt that more prolonged contact should be maintained with the hospice after the patient's death, although two people wanted to leave the door open for the possibility of future contacts. Of those who answered affirmatively, some expressed interest in participating in a bereavement group or having contact with other bereaved people.

Eighty-five percent of respondents said that it was desirable for a dying person to be at home as much as possible; two people answered that it would depend on the patient's condition, and one, that it was not desirable. Reasons given included the following: the person was more comfortable; it enabled the family to grow closer together; it enabled the patient to have some control over his life; and it enhanced the patient's will to live.

Fully 20 out of 20, or 100 percent, of the respondents said that they would recommend the program to a close friend or relative who was dying. In fact, some people already have.

In dealing with general impressions of the program, several people commented, "I don't know what I would have done without it," or, "It would have been difficult and expensive for me to manage without it." They expressed gratitude for the fact that other people were concerned with their plight; they appreciated the guidance and direction that it offered, asserting, "I think it is helpful even with a close family. . . . It gave me a secure feeling." The comment was offered on more than one occasion that the hospice member was "one of the family."

Several felt that the most valuable function of the hospice was its function as a liaison in interacting with the medical community, in making applications to nursing homes and funeral arrangements, and in helping with the delivery of hospital beds and commodes. Many people considered the hospice a valuable source of medical information. A function alluded to by some respondents was that of support. They were glad to have someone to listen to their problems, to feel their grief with them, and to tell them that they were doing a good job. This was succinctly summed up by a strong-willed 86-year-old woman, "It feels good even if they only talk and don't do anything."

Five people reported that the hospice was a better source of information regarding the patient's illness than the physician. One person said that the hospice was the *only* source of medical information and the "only link with a doctor who did not deal well with us." Some mentioned that hospice nurses were much more available than physicians.

Three respondents expressed that there was a need for hospital based hospice care. (At present, Fairview Hospice has no jurisdiction over inpatient beds.) One man felt that less costly facilities outside of the home were necessary for dying patients. One gentleman was quite saddened about circumstances surrounding his wife's final days. He was unable to care for her at home and was unable to get a hospital bed. Instead, he was forced to send her to a nursing home. It was very hard emotionally for her to make the change to the new environment. He added, "I think the change was also a signal to her that this was the end and she realized she would not see home again."

Discussion

Limitations in interpreting these findings include the following:

1. The respondent to the questionnaire was answering questions regarding another person at a previous point in time. Thus, both time and secondary evaluation of information may result in some inaccuracy.

2. It is not known how representative this group is in terms of the total population. There may have been another corresponding group of dying patients who did not require the services of a hospice.

3. The approach of the interviewer in establishing direct contact with the significant others, rather than through an indirect impersonal letter in the mail, may have biased the results. It was decided, however, that the personal contact was valuable in that the topic itself is a very personal one requiring a personal approach and the response rate would thereby be increased.

4. The people involved with the Fairview Hospice are quite sensitive and hard working and it is not clear how much of the positive results are due to their personalities rather than to the hospice concept in general.

Keeping the above in mind, it can be concluded that the contact with the Fairview Hospice was a success. Both from the answers to the questions and from the added comments, it can be concluded that people were generally satisfied with it. Significant others reported that both they and their dying relatives derived considerable benefit from the hospice. Significant others approve of the concept of a patient dying at home; they would recommend the program to others; and they managed to cope much better due to the efforts of the hospice people.

The significant others reported that they suffered more from anxiety than did the dying patients (as perceived by the significant others). Correspondingly, the relief obtained by the significant others was greater than the relief obtained by the patients. These results are supported by Lack and Buckingham's conclusions from their questionnaire,⁴ addressed directly to both parties. Thus, it would seem that the hospice can be of greater benefit to the family than to the dying patient himself.

Difficulty relating to or getting information from their physician was identified as a major problem

by 40 percent of respondents. Research by Nakamura⁵ points to communication as a major problem of the medical and other health care professions. He compared physicians' perceptions of themselves and perceptions of physicians by other professionals. The area of greatest discrepancy between the two was in the conveying of information. (This same discrepancy was identified in other professionals as well.) This, then, is an area about which physicians should be more concerned.

Surprisingly, few people identified a need for hospice centered bereavement work. Bereavement is generally looked upon as a vital function of the hospice, but this study fails to give it an important place. Perhaps the contact with the hospice enabled the family to better cope with death and thus to need less post death contact. On the other hand, one nurse commented that these people simply are not aware of their needs in this area and have to be taught them. I am hesitant, however, to ascribe needs to people that they themselves deny.

In conclusion, this study supports the view that the hospice is a valuable experience. Certainly, larger studies are needed to validate the concept and practice of the hospice, but if this study is an indication, the hospice will carve a definite niche for itself in our health care system.

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