The Role of Occupational Therapy in Hospice Care

Helen Butterfield Picard

The hospice concept seeks to help terminally ill persons to "live until they die." It holds that when the quantity of life is limited, the quality of that life should be the maximum possible. Hospice differs from the traditional models of care for the terminally ill in several major ways:

The hospice option enables the dying and their families to receive support and help, rather than continued conventional care where such treatment is no longer of value.

Palliation, not cure, is the major objective of the hospice approach. Emphasis is placed on the control of pain in its psychological, social, and spiritual, as well as physical dimensions, and on the alleviation of other distressing disease symptoms.

Care is provided by an integrated team including physicians, nurses, psychologists, social workers, allied health professionals, and other professional and lay volunteers.

Where feasible, the patient is cared for by the hospice team in his or her own home as long as it is appropriate. Approximately 30 percent of the patients, however, require care in hospice inpatient facilities. Although these facilities may be located in acute and long-term care institutions, hospice programs differ substantially from most conventional hospitals in their routine, nursing care, open visitation privileges, and highly individualized attention to the complete needs of the patient and family.

Hospice Models

St. Christopher's Hospice in England, founded by Dr. Cicely Saunders in 1967, served as an original model for the growing movement in the United States. Hospice, Incorporated, was established in 1973 in New Haven, Connecticut, as the first American hospice. From 1974 to 1981 the number of hospices has grown to more than 800 programs in varying stages of development. Although there are two basic service delivery settings for hospice care (inpatient and home care), five predominant models for service delivery exist in the United States at this time.

1. the free-standing hospice; 2. the hospital-affiliated, free-standing hospice; 3. the hospital-based hospice: (a) acute care hospital with centralized palliative care or hospice unit, (b) acute care hospice team that visits hospice patients in a scattered bed system, (c) units operated as part of a Health Maintenance Organization; 4. the hospice within an extended care facility or nursing home; 5. the home health care program: (a) hospital-based, (b) nursing home-based, (c) community-based.

According to a 1981 JCAH survey of 440 operational hospice programs, 46 percent were hospital-based, 26 percent were community-based, 23 percent were independent home health agencies, and 4 percent were totally volunteer in nature.

Hospice programs, by definition, seek to be flexible and responsive in meeting the individual needs of their patients. As a result, the patient population served by American hospices is heterogeneous in primary diagnosis, age, socioeconomic status, and sex. Yet, because increase in age and increase in incidence of terminal cancer are significantly correlated in this society, the majority of hospice patients are men and women over the age of 60, with a primary diagnosis of cancer upon admission to the hospice program.

Occupational Therapy and Hospice Care

Is there an appropriate place for occupational therapy in hospice care? Hospice care is about adding life to the patient's remaining days, not adding days to the patient's remaining life. Occupational therapy, states Holland and Nelson-Tigges, "is about realizing that a person's integrity, equality, purpose, self-esteem, mastery and adaptation rest in his ability to be purposefully engaged in regular and familiar life experiences, whether he has terminal cancer or any other problem." (1, p 375)
Given these two statements, it becomes clearer that occupational therapy can be a relevant service in hospice programs. The philosophies underlying the two are both directed toward improving patient quality of life; and, just as important, they share similar definitions of that most delicate of concepts, "quality."

Those therapists currently practicing in hospice programs demonstrate the concrete reality of Holland and Nelson-Tigges' conceptual definition. For many dying people, until hospice care begins "there is no reality except discomfort. One day is like another. With good nursing and medical care, pain and symptoms associated with advanced cancer can be abated in 4 to 6 days without addiction or detrimental side effects. Yet it is then that the real problems of living arise" (1, p 375) and it is at this point that the occupational therapist's skills may be necessary. Not all hospice patients die in a matter of days. Many live for weeks or even months. Although most are admitted with pain as a primary complaint, once the pain is controlled other important problems must be recognized and addressed. Wilkes points out the significance of the occupational therapy role at this juncture in hospice care:

If patients have lived for weeks with pain they may, when they lose it, feel lost and insecure...once the symptoms are controlled they will be worrying about their future and needing worthwhile activities...They need to work at something useful and relevant to them, or their morale will become worse. The days of the dying patient are so often few and yet empty. Work under the supervision of an experienced occupational therapist can transform the aimless atmosphere on the ward...and give dignity back to the patient. (2)

It is important here to note the phrase, "they will be worrying about their future..." Although it is generally understood that hospice patients already have or are in the process of confronting and accepting the reality of imminent death, the presence of an occupational therapist in the hospice array of services points to a continued patient need for meaning-in-life, even if that life is measured in days. Some of the stark questions an occupational therapist can help answer in hospice care are: "What shall I do tomorrow while I'm waiting to die?" and "How can I maintain as much independence as possible even while my body grows weaker each day?" Response requires creativity, insight, and giving the best of oneself.

The Future of Occupational Therapy in Hospice Programs

Hospice is careful to emphasize that the needs of dying persons must be considered on an individual basis. This principle cannot be reiterated too many times because there are strong tendencies in the health care arena to over-systematize, to reduce personal care delivery to predetermined formulae. If the complex needs of the terminally ill are to be answered well, these tendencies must be guarded against. Therefore, the use of most health care components is advised, rather than ordered, and provided accordingly. Hospices do not say "All of our patients must use the services of a __________" filling in the blank with social worker, clinical psychologist, occupational therapist, or any other professional. Instead, hospices listen closely, ask questions, and help each patient arrive at decisions about what will enable him or her to live life as comfortably and richly as possible. Hence some patients will not choose the assistance occupational therapy provides. Yet others will. We believe that, as the role of occupational therapy becomes more widely recognized and appreciated by hospices across the country, more patients will be able to have the choice of occupational therapy available to them.

Occupational therapists currently working with hospice patients should make their work known. They are encouraged to bring the pertinence of their work to the attention of their colleagues via journal articles, workshop and seminar participation, and academic liaison. Leading Congressional and Federal experts have recognized occupational therapy as an appropriate element in the hospice array of possible services. Their inclusion of occupational therapy as a Medicare-covered service in H.R. 5180 demonstrates this. It is time for hospices and occupational therapists to bring their relationship to its fullest potential. In this way, more therapists may learn of the joy of working with the dying. More hospices will learn of the relevance of occupational therapy as an available service for appropriate patients. And more dying people will have an even better chance of living their last days with as much freedom, dignity, and happiness as possible.

REFERENCES