

An Exploration of the Needs of Jewish Patients and Families in Hospice Programs in the Greater Los Angeles Area, 1982

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Introduction

In the Spring of 1982, the Jewish Hospice Commission of greater Los Angeles began to explore hospice service delivery settings available to patients and families in the greater Los Angeles area, in an attempt to identify some of the needs of Jewish patients and families cared for in these hospice programs.

Hospice as a system of caring for the terminally ill is rapidly growing and gaining acceptance among the public and health care providers. In 1981, there were some 700 hospice programs in development in the United States, and 440 hospices located in various areas in the United States.¹ The precise number of hospice programs available to the greater Los Angeles community was not precisely known at the time of the study. Although demographic studies indicated there were some one-half million Jews living in the greater Los Angeles area, there did not seem to be any studies available indicating their use or knowledge of hospice care facilities.

The purpose of this study, therefore, was to identify the hospice service delivery settings available to hospice patients and their families in the greater Los Angeles area and to assess the needs of Jewish patients and their families in these programs . . . needs, as perceived from the perspective of hospice caregivers.

The Study Method

Written and telephone contact was made with the administrative directors of the hospice programs located in the greater Los Angeles area describing the study and requesting permission for trained interviewers to call for an appointment. In addition, each hospice administrator was asked to nominate an additional staff member of their choice, in their hospice setting, so interviewers could meet with two persons from each hospice agency. Permission was granted for interviews in all instances.

An instrument was developed for data collection. Thirteen volunteer interviewers were recruited from the Jewish community, trained in basic hospice concepts and in interview techniques over a period of six weeks.

Sample

There were five hospital-based (in-patient) hospice models and nineteen mixed community/home-care-based hospice models in the greater Los Angeles area at the time of the study. There are four typical hospice models in the United States, according to McDonnell,² including hospital-based, home-care-based, free-standing, and mixed community-based. It is conceivable a few of the hospice models in the study could be defined as more than one model, but for purposes of clarity, we

¹ *Los Angeles Times*, August 30, 1982.

² Alice McDonnell, *The Organization and Administration of Hospice*. Unpublished dissertation. (New York: Columbia University, 1982).

chose to address only two basic service delivery models.

The sample of twenty-four hospice agencies in the area reflect the two basic service delivery settings for hospice care, namely in-patient and home-care. National Hospice Organization defines a hospital-based hospice program as one which is based in an acute-care hospital with a specialized palliative care or hospice unit. Our study located three such settings: Parkwood Hospice in Canoga Park, the Veterans Administration in Brentwood, and the Kaiser Permanente Hospice in Norwalk. An acute care hospital hospice consultant program consisting of a specially trained interdisciplinary hospice team, providing services to hospice patients throughout a general hospital was found in one instance, the Cedars-Sinai Medical Center Hospice Program in Los Angeles. This study identified one hospital-affiliated free-standing separate hospice facility at the Granada Hills Hospice in Granada Hills. This facility was located adjacent the Granada Hills Community Hospital with hospital staff and resources available to the Hospice.

There were no free-standing hospice facilities in the area. Both the Veterans Administration Hospice and the Kaiser Permanente Hospice had hospital-based home care programs located in these facilities designed to deliver continuing care to the patient in his/her own home. At least two programs provided hospice volunteer training exclusively and affiliated with in-patient and home-care based programs. This rich panoply of hospice programs was a microscopic view of the way in which hospice programs have developed and are developing nationally to meet particular local needs and conditions.

All hospice programs in this sample maintained extensive and comprehensive linkage systems to effect the transition of patient and family from in-

patient to care in the home and back again. Each hospice reflected the unique nature of hospice care as well as the unique nature of its delivery and development.

One of the hues and cries of the health care system has always been "fragmentation of services." The hospice programs, as a group, seemed keenly aware of this phenomenon and stressed linkage and affiliation in an attempt to preclude a lack of cohesive services.

The study team found hospice care was being delivered in a variety of settings, and did not find any facility offering only in-patient care without linkage to home-care. Some agencies specialized in home-care with linkages to hospitals, although these hospitals may not have had designated and defined hospice units. Regardless of setting, care was delivered by an interdisciplinary team composed of a physician, nurse, social worker, psychiatrist, and some combination of psychologist or clergyman. Trained volunteers and family members also always formed the core of the hospice team. The philosophy that pain is preventable and can be controlled through the use of drugs is integral to the hospice concept. The study indicated the twenty-four hospice programs were composed of teams of persons of similar professional training. All in-patient services had medical directors, registered nurses, social workers, clergy, volunteer coordinators, volunteers on staff, and access to services of an occupational therapist, speech therapist, psychologist or home health aides. Home-care agencies generally had the same staff with only a few having access to the services of psychologists and clergy.

General Findings

These twenty-four hospice agencies served some 3,007 patients in 1981; 621

patients were in care on the study date one day in the summer of 1982. The patients seemed to be evenly divided between males and females. A summary of age breakdown of patients in hospice care programs was difficult to document, although hospice agencies are required to and do keep this type of statistical data. One hospice home agency noted the average patient age was 67.8 years. One agency reported most of its patients were elderly and one agency gave the average age as 50 years.

According to McDonnell³, hospices serve patients ranging in age from twelve to eighty years, with most hospice patients in the sixty plus age group. Table I indicates 44% of our study sample patients were over the age of sixty years, a finding similar to national studies. None of the hospice programs in this sample indicated they were serving persons under the age of twenty-one years. The high proportion (41%) of persons in hospice care between the ages of forty-one and sixty years, reflected family struggles with terminal illness in the middle years.

According to a recent article in the *Journal of Commerce*, hospice programs are growing in acceptance among the public. A Washington, D.C. consulting firm suggested there were 272,000 Medicare patients in 1981 who were potential hospice patients, although only 12,000 actually received hospice care in that year.⁴ Pending hospice legislation, scheduled to become effective in November, 1983, will provide hospice benefits for the eligible aged (sixty-five years and over). Thus, thousands of dying Americans will be able to spend their last days in hospice programs, primarily at home in the home-care programs. Thus far, legisla-

³ McDonnell, *Op. Cit.*, p. 45.

⁴ *Weekly News Summary*. Blue Shield and Blue Cross Digest #18. May 3, 1982.

TABLE I
Patients in Los Angeles Hospice Programs
According to age

	Number	Percentage
40 years and under	100	15%
41-50 years	33	5%
51-60 years	239	36%
61-70 years	166	25%
71-80 years	93	14%
80 + years	33	5%
		N = 664

tion is only directed to the Medicare group. The vast majority of hospice programs in the greater Los Angeles area are planning to participate in Medicare reimbursement.

Religious Identification

Seven of the twenty-four hospice programs surveyed were unable to identify the religion of their patients. Thus, of the 664 patients in the sample, religion was identified in only 344 patients. Although only two percent of the United States population, Jews constitute about five percent of the population of greater Los Angeles.

Table II indicates 27% of all patients in hospice programs in greater Los Angeles, whose religious preferences were identified by hospice caregivers, were Jewish. Jewish patients were found within all hospice programs in the vast geographic area of Los Angeles. This finding is consonant with the 1980 Los Angeles Population Study, noting Jews are dispersed over the large Los Angeles geographic area.

TABLE II
Religious Identification of Patients in Hospice
Programs in Greater Los Angeles

	Number	Percentage
Jewish	92	27%
Catholic	50	14.5%
Protestant	90	26%
Other	15	4%
Unknown/Unidentified	97	28%
		N = 344

The vast majority of hospice programs were located in the Metropolitan and San Fernando Valley regions . . . regions known as home to high proportions of elderly and middle-age Jewish persons.⁵

There seems little questions as to utilization of the hospice system of care by the Jewish population of greater Los Angeles.

Half of the hospice agencies in the study indicated clergy on their hospice advisory boards, but only 13 percent had rabbis serving as board members. ten percent of hospice volunteers were identified as Jewish. When asked how agencies assigned volunteers to patients, religious matching of volunteer to patient-family was hardly reported, although patient-volunteer compatibility, geographic convenience for the volunteer, similar ages, mutual interests and volunteer time availability were noted.

All hospice agencies reported volunteer training programs. Approximately 70 percent of the training programs included presentations by clergy.

Jewish Needs

When asked what hospice caregivers perceived as *general* needs of their Jewish patients and families, the replies included:

1. transportation
2. money for home attendants, medication, nutritional supplements and food, insurance co-payments, rent and funerals
3. counseling
4. respite for families

When asked what hospice caregivers perceived as *specifically Jewish* needs of their Jewish patients and families, the replies included:

1. money for kosher food

2. home visits from a rabbi, especially for the non-synagogue affiliated person
3. transportation to temple or synagogues
4. information about the Jewish practices in death and arrangements
5. guidance and assistance with Jewish funeral practices and arrangements

The study revealed most hospice agencies were sensitive to special Jewish needs but were frequently unable to provide them. Hospice agencies commented they had utilized services of local Jewish communal service agencies, such as Jewish Family Service and Aides to the Elderly. With only one or two exceptions, hospice home attendants were not trained by hospice agencies to maintain the Jewish dietary laws in the home nor given specific instructions about religious practices in Jewish homes.

Comments

Although the hospice system of care stresses the importance of the need for spirituality and for religious support, this study revealed a negligible amount of specific religious content in volunteer training, agency board membership, or volunteer-patient assignments. Although hospice care concerns itself with the whole family as a unit, taking responsibility for meeting the spiritual and religious needs seemed to be the province of the patient and his/her family, rather than a component of care provided by the hospice agency.

Very few hospice home-care agencies seemed to have become involved in arrangements for celebration of Jewish holidays, provision of kosher food, and other ritual observances. In-patient hospice programs reported the availability of rabbis, kosher food, holi-

⁵ Los Angeles Jewish Community Survey. Overview in Regional Planning, 1980.

day and ritual celebrations, etc., but were infrequently called upon to support the observing Jewish patient's in-place religious regime.

The vast majority of hospice programs in this study indicated discomfort with their bereavement programs. In all likelihood, this will be an important issue for hospices on a national basis since Federal legislation for hospice reimbursement will require bereavement programs as a core service, but without specific reimbursement. It is likely bereavement services will be provided by volunteers specifically trained

for this task and/or by communities. For Jews, there is an identified and prescribed bereavement ritual which could form the basis of services to Jewish families.

Jewish cultural traditions and values provide a source of spiritual comfort and order, and a continuation of the rhythm of life for the terminally ill Jewish patient and his family. Hospice agencies serving Jewish patients and their families in the greater Los Angeles area should seek to integrate these traditions and values into the care and training offered.

**Twenty-Five Years Ago
From the Pages of this Journal of 1957-8**

Sectarianism

This brings us directly to the next question, which is the attempt to define a valid basis for continuing Jewish services under sectarian auspices.

It seems clear from our discussions that as governmental and general community services expand, the core of Jewish service will have to be defined increasingly in religious and cultural terms. Some of the groups approached this problem on the theoretical level, trying to spell out what services do or do not belong in a religious-cultural definition. In one group, this ended with a conclusion that there was no longer a valid rationale for the Jewish hospital and that this type of service no longer belongs under sectarian auspices. The rest of us commented facetiously that such a recommendation on behalf of this Conference should make us very popular in the city of Chicago. I think we recognized that there is more to this issue of sectarianism than drawing logical conclusions from a theoretical proposition, and there are certain firm realities which a strictly ideological-logical approach does not take adequately into account.

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