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A STUDY OF THE KNOWLEDGE AND USE OF HOSPICE BY HEALTH CARE PROFESSIONALS IN OMAHA

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I. INTRODUCTION AND BACKGROUND

Needs Assessment Approach

The primary objective of this study was to conduct a needs assessment for the Omaha Hospice Organization which would determine the knowledge and/or use of hospice concepts and programs by health care professionals.

A comprehensive community needs assessment is required in order to answer questions of need fully. A thorough explanation is required for such questions as: 1) How are the dying currently being cared for? 2) What are the patient and family needs? 3) What sources of help are presently available to patients and families? 4) Do barriers exist for using existing services? 5) Would patients and their families use hospice programs?

Such a comprehensive community-wide needs assessment was not possible due to limited resources and time constraints. Instead, the Community Resources and Service Committee of the Omaha Hospice Organization decided to concentrate on the knowledge of health care professionals and on use of hospice concepts and programs. The rationale includes 1) health care professionals play a vital role in educating potential clients about hospice philosophy and available programs, and 2) hospice admission criteria require a physician's order for a client to participate in a hospice program. Both are crucial if hospice programs are to be used at all.

Historical Background of Hospice in Omaha

Hospice care began in the Omaha metropolitan area in 1978, and five programs currently provide a variety of models of hospice care. Montclair Hospice provides in-patient skilled extended care within a nursing home facility. The University of Nebraska Medical Center and Bishop Clarkson Memorial Hospital offer a hospital-based hospice consultation team with beds located throughout both facilities. In this model, the hospice team visits the patient within the hospital setting. The hospice home health care model is offered through the Visiting Nurses Association. This model provides the client with intermittent care while remaining safely at home. Bergan Mercy Hospital, however, offers both in-patient beds and hospice care at home.

The constitution of the Omaha Hospice Organization provides the following definitions of hospice care and the hospice philosophy.

Definition of a Hospice Program of Care

> A hospice is a program of palliative and supportive services which provides physical, psychological, social, and spiritual care for dying persons and their families. Services are provided by a medically supervised interdisciplinary team of professionals and volunteers. Hospice services are available in both the home and an in-patient setting. Home care is provided on a part-time, intermittent, regularly scheduled, and around-the-clock on-call basis. Bereavement services are available to the family. Admission to a hospice program of care is on the basis of patient and family need.

Hospice Philosophy

> Hospice affirms life. Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortably as possible. Hospice recognizes dying as a normal process whether or not resulting from disease. Hospice neither hastens nor postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

The philosophical foundation of hospice care is derived primarily from these principles: 1) a commitment to the relief of suffering, 2) dedication to serve those who are in need, 3) a desire to provide spiritual, emotional, and physical comfort to dying persons and their families, 4) respect for those who are being cared for.

Translated into program goals, hospice programs emphasize, 1) the relief of social, emotional, and physical distress, particularly pain in all of its forms, 2) the value of home care or a home-like environment in which care can be provided, 3) the potential role of family members and friends in performing various care functions, 4) the need to monitor carefully the symptoms and progress of an illness while keeping patients and families informed, 5) the need to support and assist families as well as patients, 6) the importance of having health professionals available to help patients and families when needed, 7) the usefulness of a team approach in meeting the needs of patients and families, 8) the value of bereavement follow-up with families after the patient's death, and 9) the importance of providing hospice services to all dying persons regardless of their ability to pay.

Political Context

Hospice has no official accreditation either on the national or state level. Currently, the Omaha Hospice Organization operates under suggested guidelines from the National Hospice Organization. Hospitals, however, have established standards for hospice programs under the Commission for the Joint Accreditation of Hospitals.

Beginning in the fall of 1983, Medicare payments were extended to cover the cost of hospice services. According to the Omaha Hospice Organization, state health officials who approve Medicare will also be giving official sanction to hospice services that qualify.

One of the main functions of the Omaha Hospice Organization is to insure that the hospice concept is integrated within the health care delivery system. Although the state of Nebraska currently has no licensing regulations, the OHO has initiated the monitoring of hospice programs in Omaha through a peer review process.

Do We Need Hospice Care?

The question, "Do we need hospice care?" depends on whether there is satisfaction with the way the dying are being cared for or if resources are available to help them and their families. Hospice in our society has become the response to both the success and failure of modern health care methods. Society has recognized the success of science in prolonging life but at the same time has neglected to face the problems created for those who cannot hope to recover. The humanitarian response was the development of a care program designed to ease the distress of dying for the patients and their families.

One elementary way to assess the overall need for hospice care in a given area is to look at potential demand for such services. According to American Cancer Society statistics, approximately 169 persons per 100,000 population will die of cancer. Applying that figure to estimated population figures for the Omaha metropolitan area translates into 816 projected cancer deaths. The Nebraska State Department of Health statistics for Douglas and Sarpy Counties indicate 728 people died of cancer related causes in 1982. As helpful as these estimates might be, they do not indicate patient and family interest in utilizing hospice programs.

A guideline established by Dr. Balfour Mount, medical director of the Palliative Care Unit in Montreal, Quebec, indicates the number of hospice beds in a community should be 4 to 5 percent of the total number of cancer deaths a year in a community.[2] Based on the American Cancer Society figures, stated above 33 to 41 beds in the Omaha metropolitan area should be designated as hospice beds. Again, potential demand does not determine actual use.

Another factor that may have an impact on the need for hospice care is cost. As the cost of health care services

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[1] American Cancer Society, <u>Cancer Facts and Figures</u> (New York: 1984).

[2] United Way of the Midlands, <u>Hospice Report</u> (Omaha: June, 1980).

continues to increase, hospital costs will become so high that hospitalization will be reserved only for the most serious medical situations. Predictions indicate hospitals will be facilities for emergency care and for treatment of major acute illnesses and injuries. The home care model of hospice has already proved to be the most economical means of providing care for the dying.

II. STUDY DESIGN

The study constituted a needs assessment of health care professionals. The major focus of the report was to determine this population's knowledge and use of hospice services in Omaha. The primary purpose of the study was to produce information necessary for hospice planning and coordination.

Study questions focused on seven major concerns:

1. Are physicians and other health care professionals familiar with the purpose of hospice care?
2. What opinions have physicians and other health care professionals formed about hospice programs and what they attempt to do?
3. Are physicians and other health care professionals making referrals to hospice programs?
4. Among physicians and other health care professionals, which programs are the preferred options?
5. Have physicians and other health care professionals who have used hospice services been satisfied?
6. Do barriers exist which prevent the use of existing hospice services?
7. Is there any interest in expanding existing hospice services?

Physicians and other health care professionals constituted the population of the study. Health care professionals, other than doctors, included nurses, hospital and nursing home administrators, and social workers.

Phase One

Phase one of the study consisted of a questionnaire distributed to two groups of doctors. Group one of the target population consisted of all oncologists and internists listed in the Omaha telephone directory. Ninety-three questionnaires were mailed. A letter and follow-up questionnaire were sent out again three weeks later in hope of increasing the response rate. In all 55 questionnaires were completed and returned for a 59 percent response rate. (See Figure 1.)

FIGURE 1

	Total Number of Physicians Receiving a Questionnaire	Total Number of Physicians Responding	Response Rate
Oncologists and internists	93	55	59%
Other physicians	610	94	16%
Overall totals	703	149	21%

Group two consisted of doctors comprising the total membership of the Metropolitan Omaha Medical Society with the exception of oncologists and internists. Questionnaires were mailed to 610 doctors. A letter and follow-up questionnaire were sent out again three weeks later. In all 94 questionnaires were completed and returned for a 16 percent response rate.

Due to the small response rate for the category of other doctors, caution should be used in generalizing from the results. The low response rate may be attributed in part to the fact that this group of doctors comes in contact less frequently with the terminally ill. Fifteen of those questionnaires were returned as non-deliverable. The two-page questionnaire reviewed each doctor's knowledge and experience with hospice programs. A copy is contained in the Appendix. A letter from the vice president of the board of directors of the Omaha Hospice Organization accompanied the initial questionnaire. It stressed the significance of the study and urged cooperation. (See the Appendix.)

Phase Two

Phase two consisted of a mailed survey to other health care professionals. Other health care professionals were defined as oncology, hospice, and hospital nurses; hospital and nursing home administrators; home health care nurses; and social workers involved in direct services to dying patients and their families. Questionnaires, identical to those sent to doctors and color-coded for each profession, were mailed to a list of everyone in each population. Only Nebraska Nursing Association nurses were selected through a systematic sampling procedure because of the larger numbers in that population. The list was reviewed to eliminate duplication with other nurses. Lists were made available by the Omaha Hospice Organization. Of the 345 questionnaires distributed, 188 were completed and returned giving a response rate of 54 percent. (See Figure 2.)

FIGURE 2

	Total Number of Other Health Care Professionals Receiving the Questionnaire	Total Number of Health Care Professionals Responding	Response Rates
Oncology nurses	93	45	48%
Hospice nurses	4	3	75%
Nebraska Nursing Association	112	52	46%
Home health care nurses	41	32	78%
Hospital administrators	10	5	50%
Nursing home administrators	20	14	70%
Social workers	65	37	57%
Overall totals	345	188	54%

III. RESULTS

Contact with Terminally Ill

All health care professionals were first asked, "In the course of your work, how often are you in contact with the terminally ill?" Nearly half (46 percent, N=154) said they came in contact with the terminally one to five times weekly with responses ranging from one to three times monthly to never. Table 1 describes the responses of health care professionals to the question.

TABLE 1

FREQUENCY OF HEALTH CARE PROFESSIONALS' CONTACT WITH THE TERMINALLY ILL

	Frequency of Contact	
	Number	Percent
1-5 times weekly	154	46
1-3 times monthly	115	34
Almost never	60	18
Never	5	2
Totals	334	100

A cross-tabulation of the results by health care profession showed the majority, except those categorized as other doctors, were in contact with the terminally ill one to five times weekly. As expected, oncologists and internists (64 percent, 35 respondents) were most often in contact, but 56 percent (10 respondents) of the administrators reported they were in contact with the terminally ill one to five times weekly. Table 1-1 presents the results.

TABLE 1-1

FREQUENCY OF CONTACT WITH THE TERMINALLY ILL BY HEALTH CARE PROFESSION

	Oncologists and Internists		Other Doctors		Nurses		Administrators		Social Workers	
	No.	%	No.	%	No.	%	No.	%	No.	%*
1-5 times weekly	35	64	29	31	64	49	10	56	16	44
1-3 times monthly	16	29	41	44	41	31	5	28	12	33
Almost never	4	7	21	22	25	19	2	11	8	22
Never	0	0	3	3	1	1	1	6	0	0
Totals	55	100	94	100	131	100	18	100	36	99

*Percentages do not equal 100% due to rounding.

Are Needs Being Met?

Health care professionals were also asked if they felt the needs of the terminally ill were being met. (See Table 2.) Only 11 percent (35 respondents) felt the needs of the terminally ill were almost always met. Half (159 respondents) said these needs were frequently met. However, 39 percent (122 respondents) felt they were seldom or almost never met.

TABLE 2

ARE THE NEEDS OF THE TERMINALLY ILL BEING MET?

	Number	Percent
Almost always	35	11
Frequently	159	50
Seldom	111	35
Almost never	11	4
Never	0	0
Totals	316	100

Table 2-1 presents a cross-tabulation of the results by health care profession. Almost nine-tenths (89 percent) of the administrators reported feeling the needs were almost always or frequently being met. Perhaps this perception was based on their lack of direct and on-going contact with terminally ill patients. However, 74 percent (40 respondents) of the oncologists and internists said the needs of the terminally ill were almost always or frequently met. Other non-physician caregivers were less optimistic. For example, nearly half of the nurses (48 percent) and social workers (44 percent) said the needs of the terminally ill were seldom or almost never met.

TABLE 2-1

ARE NEEDS OF THE TERMINALLY ILL BEING MET?
(BY HEALTH CARE PROFESSION)

	Oncologists and Internists		Other Doctors		Nurses		Administrators		Social Workers	
	No.	%	No.	%	No.	%*	No.	%	No.	%
Almost always	4	7	12	14	16	13	1	6	2	6
Frequently	36	67	43	49	49	40	15	83	16	50
Seldom	12	22	31	35	53	43	2	11	13	41
Almost never	2	4	2	2	6	5	0	0	1	3
Totals	54	100	88	100	124	101	18	100	32	100

*Percentages do not equal 100% due to rounding.

Familiarity with Hospice

Almost all of the health care professionals surveyed were familiar with the purpose of hospice before receiving the survey questionnaire (98 percent, N=330). (See Table 3.)

Support of Hospice Concept

Furthermore, almost all (99 percent) of the health care professionals surveyed said they supported the concept of hospice. (See Table 4.)

TABLE 3

FAMILIARITY WITH HOSPICE BEFORE RECEIVING QUESTIONNAIRE

	Number	Percent
Yes	330	98
No	5	2
Totals	335	100

TABLE 4

SUPPORT OF THE CONCEPT OF HOSPICE

	Number	Percent
Yes	329	99
No	3	1
Totals	332	100

Professional caregivers were asked an open-ended question about their support of hospice care. (See Table 4A.) The majority of comments (71 percent) were favorable toward the concept of hospice, although some caregivers voiced reservations or raised issues concerning certain aspects.

Family and patient support are the goals of hospice service. At one end of the spectrum were those who described hospice as providing enhanced support for the patient (21 percent). Another 20 percent felt hospice provided additional support to families too. At the other end were those who felt that problems exist with some doctors accepting hospice (only 2 percent).

Further details of the support of the hospice concept by health care profession are supplied in the Appendix in Table A.

Over half (56 percent) of the total responses received (N=170) were from nurses. Nurses, more than any other caregivers, recognized death as a part of life that needs to be dealt with and worked through. For example, nurses gave 63 percent (12 respondents) of the responses supporting hospice because it assists in coping with death and dying, 63 percent (8 respondents) of the responses indicating that hospice is an optional way to care for the dying, and 82 percent of the responses indicating support because hospice allows patients another choice in the way they die. One nurse wrote, "Families and patients are more secure and comfortable in a familiar environment and with family members." Another nurse said, "Hospice is based on rights to make decisions about oneself at the moment of death."

TABLE 4A

HEALTH CARE PROFESSIONALS' COMMENTS ABOUT SUPPORTING THE CONCEPT OF HOSPICE

	Number[a]	Percent
Provides for enhanced patient support	36	21
Provides support to families	33	20
Assists in coping with death and dying	19	11
Optimal way to care for the dying	13	8
Allows the patient and family another choice	11	6
Concerns about cost	11	6
Increased need for hospice care	9	5
Problems with doctors accepting hospice	4	2
More assistance from staff needed	3	2
General comments	17	10
Other	14	8
Total comments	170	99

[a] Number of responses

Only 10 percent (N=18) of the total comments received were unfavorable. These were primarily voiced by nurses and social workers whose major concerns were cost and doctors' acceptance of hospice. General and other comments categories composed 18 percent of the total responses and contain neutral comments including anecdotes, testimonials, statements that hospice has to be determined on a case by case basis, and a comment by one nursing home administrator who opposed any duplication of services.

Referrals

Over half (52 percent) of the health care professionals surveyed said they had never referred anyone to a hospice program. (See Table 5.)

TABLE 5

REFERRALS TO HOSPICE PROGRAMS

	Number	Percent
Yes	159	48
No	174	52
Totals	333	100

Table 5-1 presents a cross-tabulation by health care profession of the question about whether the professional caregiver had ever referred anyone to a hospice program. Social workers comprised the largest group (81 percent) of those who had made referrals to hospice programs. This is understandable since a large part of the job of a social work professional involves making referrals.

TABLE 5-1

REFERRALS TO HOSPICE PROGRAM BY HEALTH CARE PROFESSION

	Oncologists and Internists		Other Doctors		Nurses		Administrators		Social Workers	
	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	40	73	28	30	56	43	6	33	29	81
No	15	27	66	70	74	57	12	67	7	19
Totals	55	100	94	100	130	100	18	100	36	100

Regardless of who makes a referral, admission to a hospice program must have the consent of the attending physician and/or medical director. Nearly three-fourths (73 percent) of the oncologists and internists reported referring patients to hospice programs. However, only 30 percent of the other doctors had made a referral.

Reasons for Making Referrals

The major reason given by health care professionals for referring patients to hospice programs was that hospice offered more support to the patient and to his or her family (42 percent). (See Table 5A.) Other reasons included: 1) offers the patient more personal care (29 percent), 2) the patient wanted to be home (8 percent), and 3) the family requested hospice (7 percent).

Table 5A-1 presents a cross-tabulation of the health care profession by the professional caregivers' reasons for making referrals to hospice programs.

TABLE 5A-1

REASONS FOR REFERRAL BY HEALTH CARE PROFESSION

	More Patient Support		More Personal Care		Patient Wanted to Be Home		Family Requested Hospice		Offers Pain Control		Doctor's Request		Offers Bereavement Follow-up		Other	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Oncologists and internists	23	28	17	30	0	0	1	7	0	0	1	33	1	50	1	7
Doctors	13	16	12	21	3	23	1	7	1	11	0	0	0	0	3	21
Nurses	28	34	19	33	3	23	11	73	6	67	0	0	1	50	6	43
Administrators	3	4	2	4	0	0	0	0	0	0	0	0	0	0	1	7
Social workers	15	18	7	12	7	54	2	13	2	22	2	67	0	0	3	21
Total responses	82	100	57	100	13	100	15	100	9	100	3	100	2	100	14	99*

*Percentages do not equal 100% due to rounding.

TABLE 5A

HEALTH CARE PROFESSIONALS' REASONS FOR
MAKING REFERRALS TO HOSPICE

	Number[a]	Percent[b]
Offers more support to patient and family	82	42
Offers patient more personal care	57	29
Patient wanted to be home	15	8
Family requested hospice	13	7
Offers pain control	9	5
Doctors' request	3	2
Offers bereavement follow-up	2	1
Other	14	7
Totals	195	101

[a] Number of responses
[b] Percentages do not equal 100% due to rounding

The majority of the health care professions surveyed viewed hospice as a humane and positive method of caring for the terminally ill. Physicians' responses indicated they made hospice referrals because of their desire to provide more support (44 percent) and more personal care (51 percent) to the patient. Nurses and social workers felt these were important reasons also, but their decision to make hospice referrals was influenced by other factors such as pain and symptom management which hospice emphasizes and the desire of the patient's family.

Satisfaction with Hospice Programs

The majority of health care professionals surveyed (91 percent) were satisfied with hospice programs. (See Table 5B.)

TABLE 5B

SATISFACTION WITH HOSPICE PROGRAMS

	Number	Percent
Yes	136	91
No	14	9
Totals	150	100

All of the other doctors (N=27) and administrators (N=6) reported being satisfied with hospice. Social workers were least satisfied (32 percent) of all professional caregivers reporting. Table 5B-1 presents the cross-tabulation by health care profession about satisfaction with hospice programs.

TABLE 5B-1

SATISFACTION WITH HOSPICE PROGRAMS BY HEALTH CARE PROFESSION

	Oncologists and Internists		Doctors		Nurses		Administrators		Social Workers	
	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	35	92	27	100	51	94	6	100	17	68
No	3	8	0	0	3	6	0	0	8	32
Totals	38	100	27	100	54	100	6	100	25	100

Dissatisfaction with Hospice Programs

Only 23 responses were received expressing dissatisfaction with hospice.

Seven respondents expressed dissatisfaction with services and six mentioned cost. Five respondents expressed concern that the hospice concept was not fully understood while two questioned the strength of bereavement services. (See Table 5C.)

TABLE 5C

REASONS FOR DISSATISFACTION WITH HOSPICE

	Number[a]	Percent
Services	7	30
Cost	6	26
Concept not understood	5	22
Bereavement services questionable	2	9
Other	3	13
Totals	23	100

[a] Number of responses

Of the 23 responses received, 83 percent were from social workers (N=11) and nurses (N=8). (See Appendix Table B for the cross-tabulation.) They voiced dissatisfaction with services and noted problems with doctors' participation and communication. For example, several felt the need for physicians to participate more fully in the hospice program. One respondent said, "Physicians need to cooperate and communicate more with one another." Several nurses and social workers raised questions about the high cost of hospice, and several commented that the hospice concept was not understood. Their concern was that the hospice concept was not well-developed and said that some agencies only thought they were practicing hospice. One respondent felt an interdisciplinary approach wasn't always used. Bereavement services were questioned by two social workers who felt they should be more structured and intensified.

Obstacles Encountered

Table 6 lists the obstacles health care professionals encountered in obtaining hospice services for their patients. The most frequently mentioned response was cost (33 percent). The next most frequent response, was that doctors were resistant to the hospice idea (23 percent). Other responses cited the limited availability of hospice outside the metro area (16 percent), limited resources (12 percent), and lack of information about hospice services (7 percent).

TABLE 6

OBSTACLES HEALTH CARE PROFESSIONALS ENCOUNTERED IN OBTAINING HOSPICE SERVICES

	Number[a]	Percent
Cost	31	33
Doctor resistant to hospice idea	22	23
Limited availability outside metro area	15	16
Limited resources[b]	11	12
Lack of information about hospice programs	7	7
Problems with patient's family	2	2
Other	7	7
Totals	95	100

[a] Number of responses

[b] The limited resources specifically mentioned were volunteers, lack of hospice beds and lack of funding.

A cross-tabulation of the obstacles encountered in obtaining hospice services by health care profession show that over half of the total responses received (51 percent) were from nurses, 26 percent were from social workers, and 15 percent were from oncologists and internists. (See Appendix Table C.) The obstacle most often encountered by nurses was that doctors were resistant to the hospice idea. Several nurses raised concerns in comments like the following: "Doctors do not seem to be aware of what is provided by hospice." "In my particular situation, the doctor did not understand the purpose of hospice." "Most opposition to hospice occurs with the doctor." "There is a lack of education on the part of the medical staff to make appropriate referrals."

Cost was a major obstacle encountered by both nurses and social workers. For example, difficulty in obtaining financial assistance for clients was mentioned by severl social workers. Lack of funding sources to help the poor client pay was also a concern. Several nurses felt in-patient services were too high, and some patients were unable to afford certain levels of care. One person felt that the more developed programs were cost prohibitive.

Obstacles most often mentioned by oncologists and internists concerned the limited availability of hospice outside the metro area and limited resources in terms of lack of beds, funding sources, and volunteers. Social workers also felt restricted in securing services for their clients because of limited resources.

Obtaining Needed Resources

The responses in Table 7 indicate that the majority of the time health care professionals were able to obtain needed resources for their clients in the 11 categories asked about. Financial counseling, transportation, counseling services, legal assistance, and self-help support groups were only somewhat harder to obtain than other services. For a cross-tabulation of the harder to obtain resources by health care profession see Appendix Table D.

TABLE 7

OBTAINING NEEDED RESOURCES FOR HOSPICE CLIENTS

	Home Health Service		Equipment		Supplies		Ostomy Supplies		Counseling Services		Support Self-help Groups		Financial Counseling		Legal Assistance		Transportation		Information and Referral		Funeral Assistance	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	126	98	120	99	111	100	84	97	98	89	96	90	80	83	47	81	84	85	108	96	74	95
No	3	2	1	1	0	0	3	3	12	11	11	10	17	18	11	19	15	15	5	4	4	5
Totals	129	100	121	100	111	100	87	100	110	100	107	100	97	101	58	100	99	100	113	100	78	100

Need for Expansion of Hospice Services in Omaha

When asked whether or not a need existed for expansion of hospice services in Omaha, 75 percent of the health care providers said yes. Fourteen percent did not feel expansion of services was necessary. (See Table 8.)

TABLE 8

NEED FOR EXPANSION OF HOSPICE SERVICES IN OMAHA

	Number	Percent
Yes	227	75
No	43	14
Don't know	33	11
Totals	303	100

Table 8-1 presents information about the perceived need for expansion of hospice services in Omaha by health care profession. While the majority in each health care profession favored expansion, more administrators (42 percent), and oncologists and internists (27 percent) were reluctant to agree. Nurses (92 percent), more than any other professional caregiver group, felt the need to expand hospice services.

TABLE 8-1

NEED FOR EXPANSION OF HOSPICE SERVICES IN OMAHA
(BY HEALTH CARE PROFESSION)

	Oncologists and Internists		Other Doctors		Nurses		Administrators		Social Workers	
	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	30	73	67	84	100	92	7	58	23	82
No	11	27	13	16	9	8	5	42	5	18
Totals	41	100	80	100	109	100	12	100	28	100

Table 8A gives the comments of professional caregivers who did not want hospice services expanded. The most frequent reasons were 1) current services should be examined first (44 percent), 2) already available programs should be publicized (22 percent), 3) hospice costs too much (15 percent), 4) existing services cover the need (11 percent), and 5) hospice philosophy can be practiced by everyone without formal programs (7 percent).

TABLE 8A

REASONS EXPANSION NOT NEEDED

	Number	Percent
Current services should be examined first	12	44
Publicize already available programs	6	22
Hospice costs too much	4	15
Existing services cover the need	3	11
Hospice philosophy can be practiced by everyone without formal programs	2	7
Totals	27	99

Reasons why hospice should not be expanded were cross-tabulated by health care profession. Almost half of the total responses received (48 percent, 13 respondents) were from physicians. The comments most often made by oncologists, internists, and other doctors were that current services should be examined first and that hospice costs too much. Nurses and administrators responding to the question felt that existing programs should be publicized. (See Table E in the Appendix.) A majority of health care professionals (80 percent) also felt that <u>new</u> programs should be developed.

Expansion of Present Programs

Respondents who indicated a need for expansion of hospice services were asked whether they thought present programs should be expanded and 99 percent responded yes. (See Table 8B.)

TABLE 8B

DO YOU FEEL PRESENT PROGRAMS SHOULD BE EXPANDED?

	Number	Percent
Yes	201	99
No	2	1
Totals	203	100

DO YOU FEEL NEW PROGRAMS SHOULD BE DEVELOPED?

	Number	Percent
Yes	130	80
No	32	20
Totals	162	100

Table 8B-1 presents information about whether new hospice programs should be developed, cross-tabulated by health care profession. The majority of professional caregivers in each category who answered the question said they should. While the majority of nurses supported development of new programs, one-fourth of this group stressed the need for better utilization of existing services, the need for more public awareness, and the need for more physician endorsement.

TABLE 8B-1

OPINIONS ABOUT DEVELOPMENT OF NEW HOSPICE PROGRAMS BY HEALTH CARE PROFESSION

	Oncologists and Internists		Doctors		Nurses		Administrators		Social Workers	
	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	20	83	36	84	53	75	3	100	18	86
No	4	17	7	16	18	25	0	0	3	14
Totals	24	100	43	100	71	100	3	100	21	100

Nurses who were positive about expansion of hospice services felt that the expansion of present programs and the development of new programs were not feasible unless funding levels were increased. The coodination of extensive volunteer support would also be needed.

IV. SUMMARY AND RECOMMENDATIONS

Views of Health Care Professionals

The majority of health care professionals surveyed viewed hospice as a humane and positive method of caring for the terminally ill.

Nearly half (46 percent) said they came in contact with the terminally ill one to five times weekly, oncologists and internists the most frequently. However, non-physician caregivers were less optimistic than physicians that the needs of the terminally ill were being met.

Almost all of the health care professionals surveyed were familiar with the purpose of hospice (98 percent) and supported it (99 percent). Furthermore, the majority of comments received (71 percent) were favorable toward the concept of hospice. Over half (56 percent) of the total responses received in support of hospice were from nurses. Nurses, more than any other caregivers, recognized death as a part of life that needs to be dealt with and worked through.

Although most health care professionals said they supported hospice, over half (52 percent) said they had never referred anyone to a hospice program. Social workers comprised the largest group of those who had made referrals. The primary reason given for referring patients to hospice programs was that hospice offered more support to the patient as well as to their families.

The majority of health care professionals surveyed (91 percent) were satisfied with hospice programs. Social workers were least satisfied, followed by nurses. They noted problems with doctors' participation and communication. Nurses and social workers most often reported encountering obstacles in getting hospice services. Cost (33 percent) and doctors' resistance to the hospice idea (23 percent) were the most frequently mentioned obstacles.

The majority of the time health care professionals were able to obtain needed resources for their clients. Financial counseling, transportation, counseling services, legal assistance, and self-help support groups were reported as being somewhat more difficult to obtain.

Three-fourths of the health care professionals felt a need existed for expansion of hospice services.

While the majority in each health care profession favored expansion, more administrators (42 percent) and oncologists and internists (27 percent) were reluctant to agree. Almost all (99 percent) felt the present program should be expanded, compared to 80 percent who felt that new programs should be developed.

Planning Recommendations

What implications do the study findings have for hospice service providers?

1) Doctors and other health care providers need to become more accustomed to thinking about the needs of dying patients from the patient's point of view.

2) Doctors and other health care professionals need to understand better that hospice care is total care or attention to the whole person. Nurses more than any other health care profession are aware of this.

3) Doctors and other health care professionals could be more aware of the purpose of hospice and variety of hospice models that are available.

4) Not all health care professionals are aware of the community resources available to help the terminally ill patients and their families.

5) Doctors and other health care professionals should become more aware that hospice provides an alternative that allows the entire health care system to meet the needs of the terminally ill better.

6) Although doctors and other health care professionals say they support hospice, over half have never referred anyone to a hospice program. The traditional health care delivery system still appears to dominate.

7) Doctors and other health care professionals are concerned that the cost of hospice services can be prohibitive, and some patients are unable to afford certain levels of care.

8) Doctors and other health care professionals indicate that the hospice concept should be further encouraged, and they generally support local hospice developments.

If hospice programs are to serve the terminally ill adequately, the above issues must be addressed. Following are some recommendations for consideration, geared toward increasing the awareness of hospice programs which in turn may increase hospice referrals.

1) A public relations strategy should be initiated to familiarize physicians and other health care professionals with the range of available hospice services, what these services do, and the requirements for obtaining them.

2) An outreach effort could begin by publicizing hospice services through the mass media (radio, television, and newspaper), or developing a brochure. The brochure could be made available to health care providers to be located in places where patients and their families could read it.

3) An advisory committee of community leaders, hospice providers, selected advocates, and families of former clients could be formed to develop and direct the public relations strategy.

4) A patient advocacy program operated in conjunction with one or more local hospitals could serve as a pilot model for identifying and serving clients as they are discharged to their own homes or another facility following hospital admission, diagnosis, and treatment.

5) A volunteer bureau to assist in providing home based care for the terminally ill could be encouraged and supported. However, voluntary service would require training and commitment.

6) A network of community churches could be developed to serve as local resource centers to provide a link between those in need of hospice services and professional service providers.

7) An advisory committee of community leaders, hospice providers, selected advocates, and families of former hospice clients could be formed to explore cost considerations so that human needs continue to be served regardless of a client's ability to pay.

8) Agencies and organizations that provide home support services for the terminally ill and their families should be encouraged to coordinate their efforts in order to provide more affordable services and to eliminate obstacles in acquiring them.

APPENDIX

Omaha
Hospice
Organization

September, 1983

Dear Dr.

The Omaha Hospice Organization (OHO), composed of representatives of each Omaha hospital, has asked the Center for Applied Urban Research of the University of Nebraska at Omaha to help them conduct a needs assessment and survey to determine interest in hospice service in the Omaha area.

As physicians, we have a special interest in the care of the dying patient and those with incurable disease, as well as the impact on their families. The role of the hospice in the lives of these people needs to be explored.

We would appreciate your taking a few minutes to fill out the enclosed questionnaire. Please return it by October 7. For your convenience the questionnaire may be used as a self-addressed, prepaid mailer. Thank you.

Sincerely yours,

Daniel M. Miller

Daniel M. Miller, M.D.
Vice President
Omaha Hospice Organization Board of Directors

DM/ms

Enclosures

7020 Cass Street · Omaha Nebraska 68132 · 402-556-6262

OMAHA HOSPICE ORGANIZATION SURVEY OF PHYSICIANS AND OTHER HEALTH CARE PROVIDERS

Please give your answers to the following questions by writing in the appropriate spaces or by circling your response from among those listed.

1. In the course of your work, how often are you in contact with persons who are terminally ill. . . . .
   1. 1-5 times weekly
   2. 1-3 times monthly
   3. Almost never
   4. Never

2. Based on your experience, do you feel the needs of terminally ill persons are currently being met?. . . . . . .
   1. Never
   2. Almost never
   3. Seldom
   4. Frequently
   5. Most always

3. Were you familiar with the purpose of hospice care before receiving this questionnaire? . . . .
   1. Yes
   2. No

A hospice is a centrally administered program of palliative and supportive services which provides physical, psychological, social, and spiritual care for terminally ill persons and their families. Its services are provided by a medically supervised interdisciplinary team of professionals and volunteers, and available in both the home and an inpatient setting. Bereavement services are available to the family. A hospice program of care is based on patient and family need and maintains a continuity of care.

4. Do you support the concept of hospice? . . . .
   1. Yes
   2. No

4a. Please comment . . . . ____________________

____

____

____

5. Have you referred anyone to a hospice program?. . . . . . .
   1. Yes IF YES go to 5a.
   2. No IF NO, please go to question 6.

5a. What were your reasons for referral? . . . . ______________________________

____

____

____

5b. Have you been satisfied with what these programs have done for patients and their families?. . . . . . .
1. Yes
2. No

5c. If no, why were you not satisfied? . . . . ______________________________

____

____

____

6. What obstacles, if any, did you encounter in attempting to obtain hospice service? . . . . ______________________________

____

7. Were you able to obtain needed resources for your hospice clients?

	Not Applicable	Yes	No	If NO, Please Explain
Home health service	8	1	2	____________
Equipment	8	1	2	____________
Supplies	8	1	2	____________
Ostomy support	8	1	2	____________
Counseling services	8	1	2	____________
Support/self help groups	8	1	2	____________
Financial counseling	8	1	2	____________
Legal assistance	8	1	2	____________
Transportation	8	1	2	____________
Information and referral	8	1	2	____________
Funeral assistance	8	1	2	____________

Other (please comment) ______________________________

____

8. Do you feel there is a need for expansion of hospice services in Omaha? . . . .
1. Yes If YES, go to 8b.
2. No If NO, please explain under 8a below.

8a. . . . . ______________________________

____

____

____

8b. If yes to question 8, do you feel. . .

	Yes	No
Present programs should be expanded?	1	2
New programs should be developed?	1	2

TABLE A

SUPPORT OF CONCEPT OF HOSPICE BY HEALTH CARE PROFESSION

	Enhanced Patient Support		Support to Family		Assists in Coping With Death and Dying		Optimal Way to Care for the Dying		Allows Family and Patient Another Choice		Concerns About Cost		Increased Need for Hospice Care		Problems With Doctors Accepting Hospice		More Assistance From Staff		More General Comments		Other		Total Responses	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Oncologists and internists	4	11	2	6	1	5	0	0	0	0	0	0	2	22	0	0	0	0	3	18	2	14	14	8
Other doctors	6	17	4	12	3	16	1	8	0	0	1	9	2	22	0	0	0	0	5	29	2	14	24	14
Nurses	21	58	22	67	12	63	8	62	9	82	5	45	4	44	4	100	1	33	3	18	7	50	96	56
Administrators	1	3	0	0	1	5	0	0	1	9	0	0	0	0	0	0	0	0	2	12	3	21	8	5
Social workers	4	11	5	15	2	11	4	31	1	9	5	45	1	11	0	0	2	67	4	24	0	0	28	16
Total responses	36	100	33	100	19	100	13	101*	11	100	11	99*	9	99*	4	100	3	100	17	101*	14	99*	170	99*

*Percentages do not equal 100% due to rounding.

TABLE B

REASONS FOR DISSATISFACTION WITH HOSPICE BY HEALTH CARE PROFESSION

	Dissatisfaction with Services		Cost		Hospice Concept Not Understood		Bereavement Services Questionable		Other		Total Responses	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Oncologists and internists	1	14	1	17	0	0	0	0	1	33	3	13
Other doctors	1	14	0	0	0	0	0	0	0	0	1	4
Nurses	2	29	3	50	3	60	0	0	0	0	8	35
Social workers	3	43	2	33	2	40	2	100	2	67	11	48
Total responses	7	100	6	100	5	100	2	100	3	100	23	100

TABLE C

OBSTACLES ENCOUNTERED IN OBTAINING HOSPICE SERVICES BY HEALTH CARE PROFESSION

	Cost		Doctor Resistant to Hospice Idea		Limited Availability Outside Metro Area		Limited Resources		Lack of Information About Hospice Programs		Problems With Patient's Family		Other		Total Responses	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Oncologists and internists	4	13	0	0	5	33	3	27	1	14	0	0	1	14	14	15
Other doctors	2	6	0	0	0	0	0	0	2	29	0	0	0	0	4	4
Nurses	10	32	19	86	6	40	2	18	4	57	2	100	5	71	48	51
Administrators	2	6	0	0	1	7	0	0	0	0	0	0	1	14	4	4
Social workers	13	42	3	14	3	20	6	55	0	0	0	0	0	0	25	26
Total responses	31	99*	22	100	15	100	11	100	7	100	2	100	7	99*	95	100

*Percentages do not equal 100% due to rounding.

TABLE D

INABILITY TO OBTAIN NEEDED RESOURCES FOR HOSPICE CLIENTS BY HEALTH CARE PROFESSION

	Financial Counseling		Transportation		Counseling Service		Legal Assistance		Support/ Self-help Group	
	No.	%	No.	%	No.	%	No.	%	No.	%
Oncologist and internist	6	35	2	13	2	17	3	27	2	18
Nurses	6	35	8	53	6	50	4	36	4	36
Administrators	1	6	0	0	1	8	1	9	1	9
Social workers	4	24	5	33	3	25	3	27	4	36
Total responses	17	100	15	99*	12	100	11	99*	11	99*

*Percentages do not equal 100% due to rounding.

TABLE E

REASONS EXPANSION NOT NEEDED CROSS-TABULATED BY HEALTH CARE PROFESSION

	Current Services Should be Examined First		Publicize Already Existing Programs		Hospice Costs Too Much		Existing Services Cover Need		Hospice Philosophy Can be Practiced by Everyone Without Formal Programs		Total Comments	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Oncologists and internists	3	25	0	0	2	50	1	33			6	22
Other doctors	5	42	0	0	1	25	1	33			7	26
Nurses	2	17	4	67	0	0	0	0	1	50	7	26
Administrators	1	8	2	33	1	25	0	0			4	15
Social workers	1	8	0	0	0	0	1	33	1	50	3	11
Totals	12	100	6	100	4	100	3	99*	2	100	27	100

*Percentages do not equal 100% due to rounding.