

Special Article

ASSISTANCE FROM FAMILY MEMBERS, FRIENDS, PAID CARE GIVERS,
AND VOLUNTEERS IN THE CARE OF TERMINALLY ILL PATIENTSEZEKIEL J. EMANUEL, M.D., PH.D., DIANE L. FAIRCLOUGH, D.P.H., JULIA SLUTSMAN, B.A., HILLEL ALPERT, M.P.M.,
DEWITT BALDWIN, M.D., AND LINDA L. EMANUEL, M.D., PH.D.**ABSTRACT**

Background In addition to medical care, dying patients often need many types of assistance, including help with transportation, nursing care, homemaking services, and personal care. We interviewed terminally ill adults and their care givers in six randomly selected areas of the United States (five metropolitan areas and one rural county) to determine how their needs for assistance were met and the frequency with which they received such assistance from family members and paid and volunteer care givers.

Methods The patients, whose physicians estimated them to have less than six months to live and who had clinically significant illness other than human immunodeficiency virus infection or the acquired immunodeficiency syndrome, were referred to the study by their physicians. Of the 1131 eligible patients, 988 (87.4 percent) consented to a detailed in-person interview conducted in English, as did 893 of the 915 eligible primary care givers (97.6 percent).

Results Of the 988 terminally ill patients, 59.4 percent were over the age of 65 years, and 51.5 percent were women. The most frequent terminal illness was cancer (in 51.8 percent of the patients), followed by heart disease (18.0 percent) and chronic obstructive pulmonary disease (10.9 percent). Four percent of the patients were in an institution, such as a nursing home, residential hospice, or hospital; the rest were living in a private residence. A need for assistance was reported by 86.8 percent of the patients; they required help with transportation (reported by 62.0 percent), homemaking services (55.2 percent), nursing care (28.7 percent), and personal care (26.0 percent). Of the care givers, 72.1 percent were women. Primary care givers were family members in 96.0 percent of cases; only 4.0 percent were unrelated. Most patients relied completely on family members and friends for assistance. A total of 15.5 percent of patients relied only on paid assistance for more than half of the types of care that they needed. Volunteers (that is, unpaid helpers who were not family members or friends) provided less than 3 percent of all care.

Conclusions In our survey of terminally ill patients, family members, usually women, provided the majority of assistance with nonmedical care. Although many people received assistance from paid care givers, very few had assistance from volunteers. (N Engl J Med 1999;341:956-63.)

©1999, Massachusetts Medical Society.

DYING patients frequently have important and wide-ranging needs for assistance in addition to the medical care received from physicians and hospitals. Previous studies have documented that a majority of terminally ill patients require assistance, including home nursing care, help with transportation, homemaking services, and personal care; that many have unmet needs for care; and that the families of dying patients take on substantial burdens in caring for them.¹⁻¹⁰ Little is known, however, about the patterns of assistance to terminally ill patients. We do not know what components of the need for care are met by family members, paid care givers, or others.

Almost all the studies of this issue were conducted more than a decade ago, before the recent concerted efforts to reduce rates of hospitalization and lengths of stay.^{1-5,7,8} These efforts may have markedly affected patients' needs for care and their arrangements to obtain assistance. Furthermore, previous studies have focused on patients with cancer or dementia,^{3-7,9,11} and their results may not be generalizable to terminally ill patients with heart disease, chronic obstructive pulmonary disease, and other illnesses. Finally, there has been little understanding of any disparities, including geographic variations, in the need for and provision of assistance to terminally ill patients. We interviewed terminally ill adults and their care givers to determine how needs for nonmedical care were being met.

METHODS**Study Sample****Overall Strategy**

Two choices guide recruitment for any study of terminally ill patients: first, whether to recruit through hospitals or outpatient settings such as physicians' offices, and second, whether to use

From the Department of Clinical Bioethics, Warren G. Magnuson Clinical Center, National Institutes of Health, Bethesda, Md. (E.J.E.); the Center for Research Methodology and Biometrics, Cancer Research Center, American Medical Center, Denver (D.L.F.); the Department of Health Policy and Management, School of Hygiene and Public Health, Johns Hopkins University, Baltimore (J.S.); Vital Science and Health, Newtonville, Mass. (H.A.); and the Institute of Ethics, American Medical Association, Chicago (D.B., L.L.E.). Address reprint requests to Dr. Ezekiel J. Emanuel at the Department of Clinical Bioethics, Warren G. Magnuson Clinical Center, National Institutes of Health, Bethesda, MD 20892-1156.

formal criteria to determine that patients have a terminal illness, such as the Acute Physiology and Chronic Health Evaluation (APACHE III),¹² or to rely on physicians' clinical assessments. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), a study of seriously ill patients, recruited subjects through five hospitals who met explicit criteria.¹³ Since many terminally ill patients are no longer hospitalized, we recruited participants through physicians' offices. In routine clinical practice — for example, in referring patients to a hospice — formal criteria for life expectancy are not used, and SUPPORT found that physicians' estimates of their patients' survival were almost as accurate as APACHE III scores¹⁴; we therefore used the physicians' judgments of whether patients were terminally ill (defined as having an expected survival of less than six months).

Selection of Sites

Within each of the four regions defined by the U.S. Census, we classified metropolitan statistical areas as having high (≥ 20 percent) or low (< 20 percent) proportions of the population enrolled in health maintenance organizations. We randomly selected four metropolitan statistical areas — one in each region — that had high managed-care penetration, as well as one metropolitan statistical area with low managed-care penetration and one rural county. The six sites were Birmingham, Alabama; Brooklyn, New York; Mesa County, Colorado; St. Louis; Tucson, Arizona; and Worcester, Massachusetts.

Identification of Physicians

Within each metropolitan statistical area, we obtained lists of physicians from state boards of medical registration and state medical societies and membership lists from the American Society of Clinical Oncology, the American College of Cardiology, the American Gastroenterological Association, and the American College of Chest Physicians. Physicians were randomly selected and mailed a letter requesting that they identify patients who had, in their opinion, a serious illness other than human immunodeficiency virus (HIV) infection or the acquired immunodeficiency syndrome (AIDS) and who were likely to live for six months or less. The letter indicated that the purpose of the study was to "learn about how [patients with serious illness] experience health care." The letter was followed by personal telephone calls to the physicians. It was up to the physicians whether or not to contact patients about the study before forwarding information to the investigators. A total of 383 physicians referred patients.

Identification and Recruitment of Patients

No patient or care giver was paid to participate. Patients were eligible to participate if they had any clinically significant illness excluding HIV infection or AIDS, had a predicted survival of less than six months (as estimated by their physicians), spoke English, had no hearing difficulty, and were competent to arrange an interview time and place and to sign a consent form. Patients could be hospitalized or reside in a nursing home, residential hospice, or other facility or could be living at home. The patients identified by their physicians were sent a letter explaining the study and a postage-paid "opt-out" card. The letter stated that the purpose of the study was to understand patients' perspective on their experience of illness and the health care that they have received. If the opt-out card was not returned, patients were contacted to arrange for an in-person interview at a site and time of their choosing. Physicians identified 1472 patients, but 341 were ineligible (194 died, 116 had become mentally incapacitated, and 31 did not speak English or had hearing impairments). Of the 1131 eligible patients, 119 declined to participate, 24 could not be located, and 988 were interviewed (response rate, 87.4 percent).

Identification and Recruitment of Care Givers

Patients were asked to identify their primary care giver, defined as the person who provided them with the most assistance. Care

givers were ineligible if they could not speak English, if they had hearing impairments, or if they were not competent to arrange an interview and sign a consent form. Of the 988 patients, 70 had no care givers, and 3 had care givers who did not speak English. Of the 915 eligible care givers, 22 declined to participate. The remaining 893 care givers were interviewed (response rate, 97.6 percent).

Survey Development

A previously outlined conceptual framework guided us in developing the survey.¹⁵ Using a literature search and information obtained through meetings with 15 focus groups and 6 in-depth interviews conducted by the Center for Survey Research in Boston, we developed the survey instruments in conjunction with the National Opinion Research Center (NORC) in Chicago. The comprehensibility and reliability of the survey instrument were pre-tested with 18 patients and 15 care givers in Cleveland and Dallas. The final survey instrument was reviewed by an expert panel.

The survey for patients contained 135 questions covering the following: symptoms; social support; communication with health care providers; spirituality; need for assistance; plans for end-of-life care; economic burden of health care; sociodemographic characteristics; views of and plans for euthanasia and physician-assisted suicide; and stress induced by the interview. The survey for care givers contained 118 questions and covered the same general areas.

Survey questions on symptoms were adapted from the Wisconsin Brief Pain Inventory,¹⁶ the Medical Outcomes Survey 36-Item Short-Form Health Survey,^{17,18} and the Eastern Cooperative Oncology Group performance measure.¹⁹ Questions on social support were adapted from the Medical Outcomes Survey Social Support Scale.²⁰ With questions from the studies by Siegel et al.⁶ and Rice et al.²¹ and SUPPORT,¹³ patients and care givers were asked to rate the patient's need for assistance on a four-point scale ranging from "none at all" to "a lot" in four areas: transportation, encompassing assistance with visits to the doctor or hospital; nursing care, including assistance with taking medicines and changing bandages for skin care; homemaking, encompassing help with preparing meals and house cleaning; and personal care, defined as assistance with such activities of daily living as bathing, dressing, and eating. We asked questions about the degree of assistance needed in each area, who provided assistance, the use of home health care agencies or hospice services, and whether additional assistance was needed. Twenty-four interviewers were specially trained by the NORC to interview terminally ill patients and their care givers, and they conducted the in-person interviews between March 1996 and March 1997.

Approval of the Study

The protocol, letters, survey instruments, and consent documents for patients and care givers were approved by the institutional review boards at the Harvard Medical School and the Dana-Farber Cancer Institute, as well as by 38 institutional review boards at facilities in the six geographic areas.

Statistical Analysis

Scores for the four areas of care were summed and rescaled (from a range of 4 to 16 to a range of 0 to 10). Patients were classified as having "substantial needs" if they had a total score of 5 or higher. Patients were classified as relying on paid assistance exclusively for the majority of areas if they reported that they used paid assistance and did not have family or volunteer assistance in at least half of the areas in which they required help.

We had two a priori hypotheses. First, women and unmarried patients would rely more on paid care givers, and second, patients who were more religious would receive more help from volunteer care givers. To test hypotheses of association between independent variables and the need for care, unmet needs, assistance from family members, and paid assistance, a two-tailed Fisher's exact test was used in two-by-two tables. Cochran's chi-square test and the

Mantel-Haenszel chi-square test were used to test hypotheses of association in larger tables in which the outcomes were unordered (items with no hierarchy) and ordered (items with a hierarchy, such as income), respectively. To identify independent correlates of dependent variables — such as relying on family members or paid workers for nonmedical care — we conducted multivariate logistic-regression analyses. All reported odds ratios are from the multivariate logistic-regression models.

In the analyses of demographic factors, the independent variables we examined included sex, age, race or ethnic group, marital status, income, health insurance (Medicare and Medicaid vs. private insurance), and the need for care in the four areas studied. In the analyses of the effect of the type of disease on the need for care, the independent variables included the presence or absence of cancer, heart disease, and chronic obstructive pulmonary disease, and additional coexisting illnesses and physical functioning. Geographic variation in rates of hospitalization, levels of need for assistance in the four areas assessed, use of family and paid care givers, and use of hospice services or home health care was assessed after adjustment for the type of disease, age, sex, marital

status, race or ethnic group, and household income.²² An F statistic was used for the joint test for significant differences among the six geographic areas. Two-sided P values below 0.05 were considered to indicate statistical significance.

RESULTS

Characteristics of the Patients

The mean age of the 988 terminally ill patients we interviewed was 66.5 years; 59.4 percent were 65 or older (Table 1). Men were significantly more likely than women to be married or living with a partner (74.4 percent vs. 45.9 percent, P<0.001); 64.8 percent of white patients, 45.2 percent of Hispanic patients, and 37.0 percent of black patients reported being married or living with a partner (P=0.001 for the overall comparison).

The most common types of terminal illness were

TABLE 1. CHARACTERISTICS OF THE TERMINALLY ILL PATIENTS IN THE STUDY, THE U.S. POPULATION IN 1997, AND THE SUBJECTS IN THE STUDY TO UNDERSTAND PROGNOSSES AND PREFERENCES FOR OUTCOMES AND RISKS OF TREATMENT (SUPPORT).*

CHARACTERISTIC	TOTAL			AGE ≥65 YEARS		
	STUDY PATIENTS (N=988)	U.S. POPULATION 198,107,000	SUPPORT SUBJECTS (N=9105)	STUDY PATIENTS (N=587)	U.S. POPULATION 34,076,000	SUPPORT SUBJECTS (N=4513)
	percentage					
Sex						
Male	48.5	48.2	43.7	53.5	41.1	54.6
Female	51.5	51.9	56.3	46.5	58.9	45.4
Race or ethnic group						
White	78.9	75.2	79.4	82.5	84.7	85.0
Black	13.7	11.2	15.3	12.6	8.0	12.0
Hispanic	3.2	9.6	3.2	1.7	4.9	1.6
Other	4.2	4.1	2.1	3.1	2.4	1.4
Education						
Eighth grade or less	14.0	7.2	16.4	20.4	18.8	22.7
Some high school	18.9	11.4	28.1	19.8	15.7	27.6
High-school graduate	27.4	33.4	27.7	24.6	34.3	25.4
Some college	21.8	19.4	15.8	17.2	12.9	13.3
College graduate	11.5	21.7	6.8	11.2	12.9	6.3
Graduate training	6.3	6.9	5.2	6.7	5.4	4.7
Religion						
Protestant	61.8	58.0	52.0	61.8	NA	48.4
Catholic	25.4	25.0	27.9	25.3	NA	28.8
Jewish	4.3	2.0	8.5	5.0	NA	13.1
Other	8.4	15.0	11.7	8.0	NA	9.7
Household income†						
<\$15,000	38.4	20.3	55.9	41.9	37.8	62.4
\$15,000–\$24,999	21.1	15.4	20.5	23.1	23.4	23.1
\$25,000–\$49,999	24.9	30.0	15.2	23.6	24.7	9.0
≥\$50,000	15.6	34.3	8.4	11.4	14.1	5.4
Marital status						
Married	59.7	59.6	53.4	57.4	55.6	52.2
Widowed	20.3	7.0	20.1	29.6	33.4	32.9
Divorced	9.0	9.9	15.2	4.9	6.8	9.7
Other	10.8	23.5	11.4	8.1	4.2	6.1

*Participants in our study were 22 to 109 years of age; the figures for the U.S. population in 1997 include only persons older than 18 years, except for the figures for level of education, which included only persons older than 25 years. Because of rounding, percentages may not total 100. Data on U.S. population are from the Bureau of the Census.²³ Data on SUPPORT subjects are from Russell Phillips and Jane Soukup (personal communication). NA denotes not available.

†In SUPPORT, income is recorded as under \$11,000 and \$11,000 to \$25,000. Consequently, the categories do not precisely match the data from our study or the Census data.

TABLE 2. USE OF HEALTH CARE SERVICES, NEED FOR CARE, AND USE OF PAID ASSISTANCE AND HOSPICE CARE.*

VARIABLE	TOTAL	BIRMINGHAM,	BROOKLYN,	MESA COUNTY,	ST. LOUIS	TUCSON,	WORCESTER,	P
	(N=988)	ALA.	N.Y.	COLO.	(N=212)	ARIZ.	MASS.	
		(N=223)	(N=119)	(N=81)		(N=192)	(N=161)	VALUE†
					percentage			
Hospitalized in previous 6 mo	66.5	64.8	65.7	46.7	73.4	56.4	72.7	0.002
Surgical procedure in previous 6 mo	36.8	44.5	36.4	37.2	32.1	32.8	40.7	0.23
ICU stay in previous 6 mo	22.3	23.4	20.9	5.0	20.1	18.2	28.2	0.01
Substantial need for care	34.7	35.3	46.5	18.0	27.1	44.7	30.5	<0.001
Substantial unmet need for care	18.6	17.7	28.5	12.5	14.5	24.2	13.1	0.008
Family assistance for any care need	92.4	98.4	78.8	93.6	91.7	92.0	93.1	<0.001
Paid assistance for a majority of types of care needed	15.5	8.1	28.7	17.2	16.5	23.0	10.8	<0.001
Use of home health care or hospice care	34.7	29.9	30.1	40.8	34.1	35.2	35.1	0.67
Use of hospice care or home health care by patients who paid for a majority of types of care needed	55.3	58.5	42.8	52.7	71.0	55.7	61.2	0.07

*The values shown are the percentages of patients in each geographic area who reported using or needing each type of care. The percentages have been adjusted for diagnosis (cancer or other illnesses), age (≥65 years or <65 years), sex, race or ethnic group, and household income. For the definition of substantial need for care, see the Methods section. ICU denotes intensive care unit.

†P values are for the F statistic comparison.

cancer (51.8 percent), heart disease (18.0 percent), and chronic obstructive pulmonary disease (10.9 percent). Overall, 476 patients had terminal illnesses other than cancer. Just over half the patients (50.2 percent) reported that they were experiencing a moderate amount or a lot of pain, 17.5 percent were bedridden more than 50 percent of the day, 70.9 percent had shortness of breath while walking one block or less, 35.5 percent had urinary or fecal incontinence, and 16.8 percent had symptoms of depression. Within the six months before the interview, 66.5 percent of the patients had been hospitalized, 36.8 percent had undergone a surgical procedure, and 22.3 percent had been admitted to an intensive care unit (ICU). There was significant geographic variation in the rates of hospitalization and admission to an ICU (Table 2). At the time of the interview, 4.0 percent of the patients were in an institutional setting, such as a nursing home, residential hospice, or hospital; all the others were in a private residence. Overall, 34.7 percent were currently receiving hospice care or home health care.

Need for Care

Overall, 86.8 percent of the terminally ill patients reported that they required at least some assistance; 62.0 percent required a lot or a moderate amount of help with transportation, 28.7 percent required nursing care, 55.2 percent needed help with homemaking, and 26.0 percent needed help with personal care. Overall, 34.7 percent of the patients had a substantial need for care. In addition, 18.2 percent of the patients who required nursing care reported that the need

TABLE 3. PRIMARY CARE GIVERS FOR TERMINALLY ILL PATIENTS.*

RELATIONSHIP TO PATIENT	OVERALL	WOMEN	MEN
	(N=893)	(N=644)	(N=249)
	percentage		
Spouse or partner	54.0	37.1	16.9
Child	26.9	19.8	7.1
Sibling	6.1	4.5	1.6
Parent	4.3	3.6	0.7
Child-in-law	1.7	1.6	0.1
Other relative	3.1	2.7	0.4
Friend	3.6	2.6	1.0
Other nonrelative	0.4	0.3	0.1
Total	100.0	72.1	27.9

*The primary care givers were identified by the terminally ill patients as the persons who provided them with the most assistance and care. Because of rounding, percentages may not total 100.

for additional care was unmet. Of the patients who needed homemaking services, 23.1 percent reported that the need for additional assistance was unmet.

Providers of Care

About three quarters (72.1 percent) of primary care givers for terminally ill patients were women (Table 3). Wives or partners, daughters, and sisters combined were the care givers in 61.4 percent of the cases. Most of the relatively unskilled assistance needed

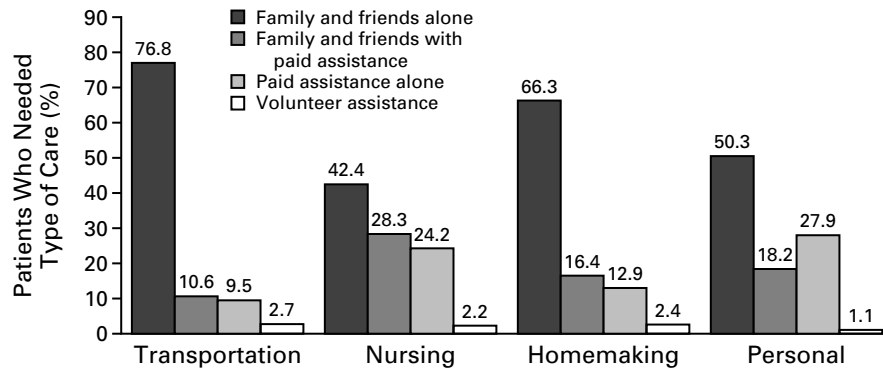


Figure 1. Provision of Assistance with Nonmedical Care to Terminally Ill Patients.

The figure shows the proportions of terminally ill patients who need a specific type of care who receive such care from family members and friends alone, family members and friends plus paid care givers, paid care givers alone, or volunteers. Volunteer assistance could be used alone or as a supplement to other forms of assistance. Percentages do not necessarily total 100 because some patients did not receive all the assistance they needed.

With respect to transportation, 0.4 percent of patients did not receive any type of assistance, and volunteer assistance was divided; 1.2 percent supplemented help from family and friends, and 1.5 percent of patients used only volunteer assistance. For nursing care, 2.9 percent of patients did not receive any type of assistance; 1.2 percent received volunteer assistance in addition to help from family and friends, and 1.0 percent received only volunteer assistance. With respect to homemaking, 2.0 percent of patients did not receive any type of assistance; 1.1 percent had volunteer assistance as a supplement to help from family and friends, 0.3 percent had volunteer assistance as a supplement to paid assistance, and 1.1 percent received only volunteer assistance. With respect to help with personal care, 2.6 percent of patients did not receive any type of assistance; 0.3 percent received volunteer assistance in addition to assistance from family and friends, 0.3 percent received both volunteer assistance and paid assistance, and 0.5 percent received only volunteer assistance.

with transportation and homemaking was provided by patients' family members and friends (Fig. 1). But even for skilled care, such as nursing, a higher proportion of patients received assistance from family members and friends than used paid care givers (Fig. 1). For instance, 50.3 percent of patients who needed help with personal care such as bathing received it from family members and friends alone, whereas 27.9 percent received only paid assistance, 18.2 percent had both help from family members and paid assistance, and 1.1 percent received volunteer help. A total of 2.6 percent were not receiving any form of assistance with personal care. The volunteer help was frequently provided in addition to family assistance; less than 5 percent of those who needed assistance relied exclusively on volunteers to meet their need for care.

There were three main patterns of assistance. Most patients relied completely on family and friends for assistance; for some, paid assistance supplemented care provided by family and friends; and others relied exclusively on paid assistance (Fig. 1). For instance, 42.4 percent of patients who needed nursing care relied exclusively on their family and friends, whereas 28.3 percent relied on a combination of family, friends, and paid workers, and 24.2 percent relied exclusively on paid help. Overall, 20.6 percent of pa-

tients who needed care relied exclusively on paid helpers to provide at least one type of assistance, with 15.5 percent relying exclusively on paid assistance for help with more than half the types of care they needed.

For patients using paid help, the vast majority of providers came from hospice programs or home care agencies; 72.2 percent of patients who used paid help for three or four of the areas of assistance received hospice care or home care. Furthermore, patients with substantial needs for assistance were more likely to want additional hospice or home care than those who did not have substantial needs (17.6 percent vs. 10.6 percent, $P=0.03$), as were patients who had unmet needs for assistance (22.9 percent vs. 10.1 percent wanted more such care, $P=0.002$) and patients who relied on paid assistance for most of the care they needed (24.7 percent vs. 11.7 percent, $P=0.03$).

Disparities in the Provision of Nonmedical Care

In the univariate analyses, terminally ill patients who were female, black, 65 years of age or older, and unmarried received significantly less assistance with nonmedical care from family members and friends and relied more on paid helpers. For instance, among the patients who needed nursing care, 64.3 percent of the women received help from family and friends,

as compared with 78.3 percent of the men ($P=0.002$). Consequently, 63.3 percent of terminally ill women required paid assistance for nursing care, as compared with 44.2 percent of terminally ill men ($P<0.001$). Similarly, 86.0 percent of married patients received nursing care from their family and friends and 44.1 percent used paid nursing assistance, but only 52.5 percent of unmarried patients had assistance from family and friends and 65.4 percent paid for nursing assistance ($P<0.001$).

In the multivariate analyses, patients who were unmarried were less likely than married patients to receive assistance from family and friends in three or more areas (odds ratio, 0.41; 95 percent confidence interval, 0.28 to 0.60). By contrast, patients with household incomes below \$15,000 were more likely than others to receive assistance from family and friends in three or more areas (odds ratio, 1.61; 95 percent confidence interval, 1.12 to 2.31). Regarding paid assistance, female sex, unmarried status, household income below \$15,000, and an age of 65 years or older were all independently associated with receiving paid assistance for any type of care (female sex: odds ratio, 2.05; 95 percent confidence interval, 1.22 to 3.45; unmarried status: odds ratio, 2.19; 95 percent confidence interval, 1.27 to 3.77; income under \$15,000: odds ratio, 2.22; 95 percent confidence interval, 1.33 to 3.71; and an age of 65 years or older: odds ratio, 2.61; 95 percent confidence interval, 1.45 to 4.70). Being unmarried, being 65 years of age or older, and having an income under \$15,000 per year were independently associated with having to rely exclusively on paid assistance to provide the majority of types of care that they needed (unmarried status: odds ratio, 2.98; 95 percent confidence interval, 1.81 to 4.92; age over 65 years: odds ratio, 2.42; 95 percent confidence interval, 1.41 to 4.15; and income under \$15,000: odds ratio, 1.76; 95 percent confidence interval, 1.11 to 2.80). Married patients with low incomes were more likely to receive family assistance (as did 59.4 percent of low-income, married patients, as compared with 38.0 percent of low-income, unmarried patients; $P=0.007$), whereas more low-income, unmarried patients relied on paid care givers (35.1 percent of low-income, unmarried patients vs. 16.7 percent of low-income, married patients; $P=0.001$).

Volunteer Care Givers

Only 4.0 percent of care givers were unrelated to the patients (Table 3). Furthermore, only 2.7 percent of the terminally ill patients received volunteer help with transportation, and 2.4 percent received volunteer assistance with homemaking (Fig. 1). Terminally ill patients who reported themselves to be either very religious or part of a religious community that provided emotional support were no more likely to receive volunteer assistance than those who were not religious (data not shown).

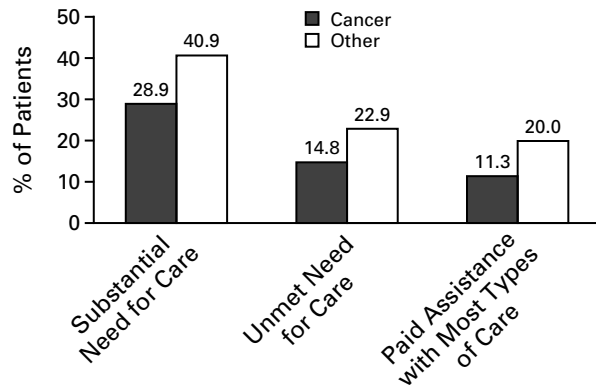


Figure 2. Need for Care among Terminally Ill Patients with Cancer or Other Diseases.

The figure shows the proportions of terminally ill patients with cancer and other illnesses who reported a substantial need for care overall (for transportation, nursing care, homemaking assistance, and personal care), who had unmet needs for nursing care and homemaking assistance, and who relied on paid assistance for a majority of the types of care they needed. $P<0.001$ for all three comparisons.

Type of Disease and Need for Care

Patients with cancer needed less assistance and had fewer unmet needs than patients with other terminal illnesses, and they were less likely to rely on paid assistance to meet their needs (Fig. 2). These differences were not due to differences in physical function or the imminence of death, since a similar proportion of both groups of patients were confined to their beds for more than 50 percent of the day (17.8 percent of patients with cancer and 16.9 percent of those with other illnesses, $P=0.74$) and patients with cancer were significantly more likely than others to die in the four months after the interview (36.8 percent vs. 18.4 percent, $P<0.001$). These differences notwithstanding, patients with illnesses other than cancer were significantly more likely to receive hospice care or home health care (29.6 percent vs. 39.0 percent, $P<0.001$).

Geographic Variation

After we controlled for the type of disease and the patient’s age, sex, marital status, race or ethnic group, and income, there was significant variation among the geographic areas in the proportion of terminally ill patients who had a substantial need for care, who had unmet needs, and who relied on either family members or paid workers for assistance (Table 2). However, there was no significant geographic variation in the proportion of patients receiving hospice care or home health care.

DISCUSSION

Consistent with earlier research, our study found that most terminally ill patients had nonmedical

needs requiring assistance. They were more likely to need help with transportation and homemaking than to need nursing services or assistance with activities of daily living. Family members and friends provided care for the majority of patients in need, even providing nursing and personal care, which require skills on the part of the care giver. We believe our society should recognize and support the substantial amount of time family members devote to caring for terminally ill patients, whether through tax credits or by other means.

About 15 percent of the terminally ill patients who required nonmedical care used only paid help to meet a majority of their needs. These patients were significantly more likely to be unmarried than married, poor than better off, and 65 years of age or older rather than younger. Such patients are likely to be adversely affected by proposed increases in copayments for home health care services and limitations on such services in the federal Medicare program.^{20,21} Patients who relied on paid assistance were significantly more likely than others to have an unmet need for care; the increased costs of paid assistance could exacerbate the gap between the care such patients need and the care they receive.

Women are doubly affected by the need for care at the end of life. Almost three quarters of all care for dying patients was provided by women. At the same time, women who needed care received less assistance from family members than men and were more likely to have to pay for assistance. In part, the inability of women to receive assistance from family and friends is related to the fact that terminally ill women were less likely than men to have a spouse or partner. However, even when they were married, women used more paid help. Women are apparently called on to provide care to dying family members, but when they themselves are dying, they must rely to a significantly greater extent on paid help.

The patients who were dying of cancer needed less assistance, had fewer unmet needs, and relied less on paid assistance than the patients with other terminal illnesses. This may be so partially because physicians are more comfortable viewing patients with cancer as dying²⁴ and are therefore more ready to arrange appropriate supportive services. Physicians may also be less skilled at assessing the needs of terminally ill patients with other illnesses. Furthermore, because of the many exacerbations and remissions they experience, terminally ill patients with heart failure and other illnesses besides cancer may require assistance over a longer period. This pattern may tax their families, thus requiring more paid assistance and creating more unmet needs. These disparities existed in our study group despite the greater use of hospice care and home health care by patients with illnesses other than cancer. Current assistance designed for patients with cancer, such as

time limits on the use of hospice care, may be inappropriate for patients with other terminal illnesses.

Our data also demonstrate that the amount of volunteer assistance provided to terminally ill patients is negligible. Only 4.0 percent of patients had nonrelatives as their primary care givers, and less than 3 percent of patients who needed care reported that they received volunteer assistance. Church, synagogue, or mosque members, work colleagues, and other nonfamily care givers are not integrally engaged in assisting in the care of most dying patients.

Our study has several limitations. The study population may not be totally representative of dying patients in the United States. Over half the patients had cancer, but cancer causes only 23 percent of deaths (although this is in part because people who died suddenly from heart disease or accidents were not part of our study). Similarly, we excluded patients with dementia and HIV infection or AIDS. Furthermore, physicians' identification of terminally ill patients could have been biased. Physicians may have selectively referred only "good" patients, such as those with fewer symptoms, those who were more compliant, and those with a family network or social connections. Because of the sensitivity of interviewing terminally ill patients, we — like previous investigators^{10,13,25} — obtained the physician's consent before interviewing a patient. Physicians are more comfortable predicting death within six months for patients with cancer than for those with other illnesses; the possibility of exacerbations and remissions, as well as sudden death, makes predicting six-month mortality for patients with diseases other than cancer more uncertain.^{13,26} Since patients with cancer fared better overall, the higher proportion of such patients probably provided us with a "best-case" scenario. We also relied on patients' reports without objective assessment of their need for care or the assistance they received.²⁷ Similar subjective assessments of the need for care have been used previously and are essential for understanding the experiences of dying patients.^{3-6,10,13}

Because of increased use of home health care and other forms of paid assistance and concern about fraud, there have recently been efforts to reduce the use of such care.^{28,29} Restrictive policies are likely to have adverse effects on many terminally ill patients, especially those who are most likely to rely on paid assistance — women, blacks, widowed patients, and the elderly. Before policies are widely implemented, their impact on terminally ill patients should be thoroughly evaluated. In addition, we need to develop better means of meeting the needs of terminally ill patients who have illnesses other than cancer.

Our data also suggest that men and members of religious and other civic organizations have an opportunity to be more actively engaged in caring for terminally ill patients. Finally, declines in marriage

rates and higher divorce rates could portend increasing reliance in the future on paid workers to provide the nonmedical care needed by terminally ill patients, thereby increasing health care costs.

Supported by grants from the Commonwealth Fund and the Nathan Cummings Foundation.

We are indebted to Drs. Marion Danis, Lee Goldman, and Russell Phillips for their advice on the project and their criticisms and comments on the manuscript; to Alma Kuby and the NORC for conducting the interviews; and to Brad Kaiser for preparing the figures.

The opinions expressed in this article are those of the authors and do not necessarily reflect the opinions or policies of the National Institutes of Health or the Department of Health and Human Services.

REFERENCES

- Johnson CL, Catalano DJ. A longitudinal study of family supports to impaired elderly. *Gerontologist* 1983;23:612-8.
- Heinrich RL, Schag CC, Ganz PA. Living with cancer: the Cancer Inventory of Problem Situations. *J Clin Psychol* 1984;40:972-80.
- Greer DS, Mor V, Morris JN, Sherwood S, Kidder D, Birnbaum H. An alternative to terminal care: results of the National Hospice Study. *J Chronic Dis* 1985;39:9-26.
- Mor V, Guadagnoli E, Wool M. An examination of the concrete service needs of advanced cancer patients. *J Psychosoc Oncol* 1987;5:1-17.
- Houts PS, Yasko JM, Harvey HA, et al. Unmet needs of persons with cancer in Pennsylvania during the period of terminal care. *Cancer* 1988;62:627-34.
- Siegel K, Raveis VH, Houts P, Mor V. Care burden and unmet patient needs. *Cancer* 1991;68:1131-40.
- George LK, Gwyther LP. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist* 1986;26:253-9.
- Pruchno RA, Potashnik SL. Caregiving spouses: physical and mental health in perspective. *J Am Geriatr Soc* 1989;37:697-705.
- Kissane DW, Bloch S, Burns WI, McKenzies D, Posterino M. Psychological morbidity in the families of patients with cancer. *Psychooncology* 1994;3:47-56.
- Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. *JAMA* 1994;272:1839-44.
- Max W, Webber P, Fox P. Alzheimer's disease: the unpaid burden of caring. *J Aging Health* 1995;7:179-99.
- Knaus WA, Wagner DP, Draper EA, et al. The APACHE III prognostic system: risk prediction of hospital mortality for critically ill hospitalized adults. *Chest* 1991;100:1619-36.
- The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA* 1995;274:1591-8. [Erratum, *JAMA* 1996;275:1232.]
- Knaus WA, Harrell FE Jr, Lynn J, et al. The SUPPORT prognostic model: objective estimates of survival for seriously ill hospitalized adults. *Ann Intern Med* 1995;122:191-203.
- Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet* 1998;351:Suppl 2:S1121-S1129.
- Daut R, Cleeland S, Flanery R. Development of the Wisconsin Brief Pain questionnaire to assess pain in cancer and other diseases. *Pain* 1988;17:197-210.
- Ware JE. SF-36 health survey: manual and interpretation guide. Boston: Health Institute, New England Medical Center, 1993.
- Berwick DM, Murphy JM, Goldman PA, Ware JE Jr, Barsky AJ, Weinstein MC. Performance of a five-item mental health screening test. *Med Care* 1991;29:169-76.
- Zubrod CG, Schneiderman M, Frei E III, et al. Appraisal of methods for the study of chemotherapy of cancer in man: comparative therapeutic trial of nitrogen mustard and triethylene thiophosphoramide. *J Chronic Dis* 1960;11:7-33.
- Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med* 1991;32:705-14.
- Rice DP, Fox PJ, Max W, et al. The economic burden of Alzheimer's disease care. *Health Aff (Millwood)* 1993;12(2):164-76.
- Kleinbaum DG, Kupper LL, Muller KE. Applied regression analysis and other multivariable methods. 2nd ed. Boston: PWS-Kent Publishing, 1988.
- Bureau of the Census. Statistical abstracts of the United States: 1998. 117th ed. Washington, D.C.: Government Printing Office, 1998.
- Wachter RM, Luce JM, Hearst N, Lo B. Decisions about resuscitation: inequities among patients with different diseases but similar prognoses. *Ann Intern Med* 1989;111:525-32.
- Ganzini L, Johnston WS, McFarland BH, Tolle SW, Lee MA. Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *N Engl J Med* 1998;339:967-73.
- Field MJ, Cassel CK, eds. Approaching death: improving care at the end of life. Washington, D.C.: National Academy Press, 1997:50-86.
- Taylor RJ, Chatters LM. Extended family networks of older black adults. *J Gerontol* 1991;46:S210-S217.
- Panel urges co-pay for home visits to Medicare patients. *Washington Post*. March 4, 1998:A13.
- Meyer H. Home health on the high wire: in the search for Medicare savings, politicians sidestep important structural questions. *Hosp Health Netw* 1997;71:26-9.