Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and Their Caregivers

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Background: Terminal illness imposes substantial burdens—economic and otherwise—on patients and caregivers. The cause of these burdens is not understood.

Objective: To determine the mechanism for economic and noneconomic burdens of terminal illness and to identify potential ameliorating interventions.

Design: In-person interviews of terminally ill patients and their caregivers.

Setting: Six randomly selected U.S. sites: Worcester, Massachusetts; St. Louis, Missouri; Tucson, Arizona; Birmingham, Alabama; Brooklyn, New York; and Mesa County, Colorado.

Participants: 988 terminally ill patients and 893 caregivers.

Measurements: Needs for transportation, nursing care, homemaking, and personal care; subjective perception of economic burden; expenditure of more than 10% of house-hold income on health care costs; caregiver depression and sense of interference with his or her life; and patient consideration of euthanasia or physician-assisted suicide.

Results: Of all patients, 34.7% had substantial care needs. Patients who had substantial care needs were more likely to report that they had a subjective sense of economic burden (44.9% compared with 35.3%; difference, 9.6 percentage points [95% CI, 3.1 to 16.1]; P = 0.005); that 10% of their household income was spent on health care (28.0% compared with 17.0%; difference, 11.0 percentage points [CI, 4.8 to 17.1]; $P \leq 0.001$); and that they or their families had to take out a loan or mortgage, spend their savings, or obtain an additional job (16.3% compared with 10.2%; difference, 6.1 percentage points [CI, 1.4 to 10.6]; P = 0.004). Patients with substantial care needs were more likely to consider euthanasia or physician-assisted suicide (P = 0.001). Caregivers of these patients were more likely to have depressive symptoms (31.4% compared with 24.8%; difference, 6.6 percentage points [CI, 0.4 to 12.8]; P = 0.01) and to report that caring for the patients interfered with their lives (35.6% compared with 24.3%; difference, 11.3 percentage points [Cl, 5.0 to 17.7]; P = 0.001). Caregivers of patients whose physicians listened to patients' and caregivers' needs had fewer burdens.

Conclusions: Substantial care needs are an important cause of the economic and other burdens imposed by terminal illness. Through empathy, physicians may be able to ameliorate some of these burdens.

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Serious illness has an adverse effect on patients, family, and friends. Previous studies have demonstrated that caregivers of patients with cancer and dementia have increased health problems and psychosocial stress (1–7). For example, studies have reported that up to one third of spouses of patients with terminal cancer have depressive symptoms (8, 9). Families of terminally ill patients also experience adverse economic effects. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) reported that families of seriously ill patients experienced substantial economic losses. In 20% of families, a family member had to stop working; 31% of families lost most of their savings (7).

Data on the cause of these adverse effects are scarce. The SUPPORT investigators stated, "Although our results document substantial burdens to family members of seriously ill patients, they do not explain the mechanism of these burdens . . . Our results highlight the need for future research efforts to examine the mechanism of these burdens" (7). In addition, without understanding the cause of these burdens, it is difficult to identify interventions that could meet the care needs of terminally ill patients without imposing additional hardships on their families and friends.

To determine the cause of economic and other burdens and to identify some potential interventions that could mitigate them, we studied the experiences of 988 terminally ill patients with different illnesses and their 893 caregivers.

Methods

Recruitment

Our methods have been described in detail elsewhere (10) and are outlined in **Figure 1**. Briefly, patients were recruited on the basis of physician determination of terminal status. Because many terminally ill patients are no longer admitted to hospitals and do not die in hospitals, we recruited through outpatient settings. Similarly, because SUPPORT found that patients' 6-month survival rates determined by physicians were almost as accurate as those determined by using formal medical criteria (11) and because in routine practice, such as hospice referral, physicians determine terminal ill-



Figure 1. Flow diagram of patient identification and enrollment. CMSA = consolidated metropolitan statistical area.

ness without using formal criteria, we relied on physician determination of patients' terminal status.

Site Selection

We divided all 50 states into four census regions: northeast, south, midwest, and west. The Group

Health Association of America issued a report on the proportion of the insured population that was enrolled in health maintenance organizations (HMOs) in the 54 largest metropolitan statistical areas (MSAs) (12). According to this report, we classified MSAs as having high or low managed care penetration. *High penetration* was defined as HMO enrollment of 20% or more of the population in 1991, the last year for which managed care penetration data were available before site selection. In each of the four regions, one MSA with high HMO penetration was randomly selected: Worcester, Massachusetts; St. Louis, Missouri; Tucson, Arizona; and Birmingham, Alabama. Among the MSAs with low penetration, one site was selected: Brooklyn, New York. To represent the 24% of the U.S. population that resides in rural areas, one site was randomly selected among all non-MSA primary sampling units (that is, all non-MSA counties or collections of counties): Mesa County, Colorado.

Physician Identification

At each site, lists of physicians were obtained from state boards of medical registration, medical societies, and specialty societies. From these lists, physicians were selected by simple random sampling that aimed for the same patient sample size in each site. At the rural site, however, all physicians were selected because of small numbers. Selected physicians were mailed a letter stating that the purpose of the study was to "learn about how these patients [with significant illness] experience health care" and that patient and caregiver interviews would be done in person. Physicians were asked to identify all of their patients who had "a significant illness [except HIV infection or AIDS] and a survival time of six months or less, in your opinion." The physicians used their own discretion to decide whether to discuss the study with patients before identifying them. A total of 383 physicians referred patients, whom we then interviewed.

Patient Selection

No patient or caregiver was paid to participate in the study. Patients were eligible to participate if they had any substantial illness, excluding HIV infection or AIDS; had an estimated survival time of less than 6 months, as determined by their physician; spoke English; had no hearing difficulty; and were able to arrange an interview time and place and sign a consent form. Patients were not randomly selected; instead, all patients identified by physicians were sent a letter that explained the study and included a postage-paid "opt-out" card. The letter stated that the study aimed to understand "the attitudes of patients with a significant illness and their caregivers towards the quality of the patient's health care." Patients were informed that the interview would be conducted in person. If the opt-out card was not received within 2 weeks, the patient was contacted to arrange an interview.

Physicians identified 1472 patients, of which 341 were ineligible (194 died and 116 became mentally incapacitated before being interviewed; 31 did not speak English or had hearing limitations that precluded interviews). Of the 1131 eligible patients, 119 declined to participate, 24 could not be located, and 988 completed interviews (response rate, 87.4%).

Caregiver Selection

Patients were asked to identify their primary caregiver, who was specified as the family member, friend, or other person who provided the most assistance. Caregivers were ineligible if they could not speak English, had hearing limitations that prevented them from understanding questions, or were not able to arrange an interview time and place or sign a consent form. Seventy of 988 patients reported that they did not have caregivers. Three caregivers did not speak English, and 22 caretakers declined to participate. Therefore, 893 caregivers were interviewed (response rate, 97.6%).

Survey Development

Survey development was guided by a conceptual framework that has been outlined elsewhere (13). In conjunction with the Center for Survey Research and the National Opinion Research Center, we developed survey instruments after 1) performing a literature search; 2) conducting 15 focus groups that included patients, caregivers, elderly persons, and health care providers; 3) conducting six in-depth interviews with terminally ill patients and caregivers; 4) creating the survey instruments; 5) conducting cognitive, behavioral, and reliability pretests; 6) submitting the survey instruments for review by an expert panel; and 7) refining the final survey. Eighteen patients and 15 caregivers in Cleveland, Ohio, and Dallas, Texas, pretested the survey instruments.

The patient survey contained 135 questions, and the caregiver survey contained 118 questions. Questions focused on health status and symptoms, social supports, communication with health care providers, personal and spiritual meaning, care needs, end-oflife care plans, economic burdens, sociodemographic characteristics, euthanasia and physician-assisted suicide, and interview-related stress.

Survey questions on symptoms were adapted from the Wisconsin Brief Pain Questionnaire (14), the Medical Outcomes Study 36-Item Short-Form Health Survey (15, 16), and the Eastern Oncology Cooperative Group performance measure (17). Questions on social supports were adapted from the Medical Outcomes Study social support survey (18).

Using questions from Siegel and colleagues (4), Rice and coworkers (19), and SUPPORT (7, 20), we asked patients and caregivers about their need for assistance in four areas: transportation, nursing care, homemaking, and personal physical care. Questions determined the degree of assistance needed in each area, the person who provided assistance, the use of home health care or hospice services, and any unmet needs for additional assistance. Questions regarding economic burdens and financial expenditures on health care were taken from Epstein and colleagues (21) and Covinsky and coworkers (7). Some questions on physician-patient communication were adapted from SUPPORT (20). Questions on euthanasia and physician-assisted suicide were adapted from Emanuel and colleagues (22). Some of the questions on physician-patient communication, personal meaning, advance care planning, and economic burdens of care were newly developed. The instruments are available from the authors.

Interview Process

Twenty-four interviewers from the National Opinion Research Center who were trained to interview terminally ill patients conducted all interviews in person between March 1996 and March 1997.

Human Subjects Approval

The protocol, letters, survey instruments, and consent documents were approved by the institutional review boards at Harvard Medical School and the Dana-Farber Cancer Institute (Boston, Massachusetts), as well as at 38 medical institutions in the six study sites. The patient identification and selection procedures were approved as being consistent with the recommendations of the institutional review board guidebook (23). We ensured that participants had no emotional contraindications to study involvement by asking physicians to recommend appropriate patients. The investigators kept patients' personal information confidential and did not use it for any commercial purposes. The identifying information did not include data on extremely sensitive matters, such as history of drug abuse, sexually transmitted diseases, or psychiatric illness. Patients were able to decline participation through the optout card, when they were contacted to arrange an interview, when the interviewer arrived to conduct the interview, and at any point during the interview.

Statistical Analysis

Each patient was asked to rate the amount of assistance he or she needed in four areas—transportation, nursing care, homemaking, and personal care—on a four-point scale, ranging from "none at

Characteristic	Overall Patient Cohort			Patients 65 Years of Age and Older		
	Current Study	U.S. Population	SUPPORT	Current Study	U.S. Population	SUPPORT
	<%%%%%					
Sex						
Male	48.5	48.2	43.7	53.5	41.1	54.6
Female	51.5	51.8	57.3	46.5	58.9	45.4
Ethnicity						
White	78.9	75.2	79.4	82.5	84.7	85.0
African American	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						
8th 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	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 school	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
Yearly incomet						
<\$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-\$49 000	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

Table.	Characteristics of Terminally III Patients Compared with the U.S. Population and the Study to Understand
	Prognoses and Preferences for Outcomes and Risks of Treatment Sample*

* Participants in our study ranged in age from 22 to 109 years. Figures for the U.S. population in 1997 include only persons older than 18 years, except for the figures for education, which include persons older than 25 years of age. Percentages may not equal 100 because of rounding. Data on U.S. population are taken from reference 24. Data on SUPPORT cohorts were provided by R. Phillips and J. Soukup (personal communication). NA = not available; SUPPORT = Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.

+ In SUPPORT, income is recorded as less than \$11 000 or as \$11 000 to \$25 000. Consequently, the categories do not precisely match U.S. population data or data from our study.

all" to "a lot." Scores from the four areas were summed and rescaled so that the scores had a range of 0 to 10, with 10 being the greatest need for care. *High care needs* were defined as a score of more than 7.5, *moderate care needs* were defined as a score of 5.1 to 7.5, *some care needs* were defined as a score of 2.5 to 5.0, and *low or no care needs* were defined as a score less than 2.5. *Substantial care needs* were defined as moderate or high care needs (a score of 5.0 to 10). Similarly, each patient was asked to rate his or her unmet needs for nursing care and homemaking. Scores were summed and rescaled in the same manner.

Univariate tests of association between levels of care needs and patient characteristics used the Mantel–Haenszel chi-square statistic for ordered categorical outcomes. To retain efficiency and power, and because none of the outcomes had bimodal distributions, the outcomes were divided at the median unless an obvious division was dictated by the meaning of the responses. Multivariate logistic regression was used to identify the characteristics that were independently associated with substantial care needs. Statistically significant groups of factors were first identified from potential explanatory variables in five groups. The five groups were patient demographic characteristics (age, sex, marital status, income, ethnicity, education, indicators of religious affiliation, and geography), health-related symptoms (performance status, pain, depressive symptoms, shortness of breath, and incontinence), diagnostic factors (diagnosis of cancer, heart disease, or chronic obstructive pulmonary disease; length of illness; and hospitalization in the previous 6 months), economic factors (insurance status, out-of-pocket expenses for health care [excluding insurance premiums] of more than 10% of income, subjectively perceived economic hardship, and use of home care or hospice), and communication factors (trust in physician, availability of clear information from the provider, and the ability to talk freely about the end of life).

To minimize the type I errors associated with the exploratory nature of the analysis and to minimize statistically significant but clinically insignificant factors, the α value was set at 0.05 for the type I error rate of each group of explanatory variables—that is, the criteria for the likelihood ratio test for all factors from the group. If statistical significance (P < 0.05) was observed for the group, the α value was

set at 0.01 for the selection criteria for each explanatory variable. The final model was developed from the factors that were the strongest explanatory variables from each group, as determined by the highest chi-square value. The model was determined to be clinically meaningful if the results were consistent with the previously available data, if the direction of association did not change when going from the univariate tests of association to the multivariate model, and if no unreasonable assumptions had to be made about the outcomes.

Association between level of care needs and the patient's or caregiver's burden were tested by using the Mantel-Haenszel chi-square statistic for ordered categorical outcomes. Computations were performed by using Proc Logistic, version 6.12 (SAS Institute, Cary, North Carolina).

Results

Characteristics of Terminally III Patients

The sociodemographic characteristics of the 988 terminally ill patients are comparable to those seen in the U.S. population and SUPPORT (**Table**). (SUPPORT data were provided by R. Phillips and J. Soukup. Personal communication.) In our study, the mean age of the terminally ill patients was 66.5 years (range, 22 to 109 years), and 59.4% of patients were at least 65 years of age. The leading causes of terminal illness were cancer (51.8%), heart disease (18.0%), and chronic obstructive pulmonary disease (10.9%). Among all patients, 50.2% experienced substantial pain, 17.5% were bedridden for more than 50% of the day, 70.9% had shortness of breath while walking one block or less, 35.5% had urinary or fecal incontinence, and 16.8% had

depressive symptoms. In the previous 6 months, 33.5% of the patients had not been hospitalized, 36.8% had undergone a surgical procedure, and 22.3% had required a hospital stay involving a period in the intensive care unit.

Care Needs of Terminally III Patients

Overall, 16.3% of terminally ill patients had high care needs for transportation, nursing care, homemaking, and personal care. An additional 18.4% had moderate care needs, 26.0% had some care needs, and 39.2% had little or no care needs. Of patients who had high or moderate care needs, 62.0% needed transportation assistance, 28.7% needed nursing care, 55.2% needed homemaking assistance, and 26.0% needed personal care. In addition, 18.2% of patients had unmet needs for nursing care and 23.1% had unmet homemaking needs.

Predictors of Substantial Care Needs and Unmet Needs

In univariate analysis, terminally ill patients with poor physical function, pain, incontinence, shortness of breath while walking one block, or depressive symptoms had significantly greater care needs ($P \le$ 0.001). For example, 36.7% of patients with shortness of breath but only 25.6% of patients without shortness of breath had substantial care needs (P <0.001). Similarly, 75.0% of patients who were bedridden for more than 50% of the day but only 26.2% of those who were not had substantial care needs (P < 0.001).

In addition, univariate analysis showed significant disparities in care needs according to sex, ethnicity, age, and income but not according to marital or insurance status. For example, 42.0% of African-



Figure 2. Effect of care needs and economic burdens on terminally ill patients. White bars indicate patients with few care needs; striped bars indicate patients with substantial care needs. **P* = 0.005; ***P* = 0.001; ****P* = 0.004.



Figure 3. Effect of care needs on caregivers of terminally ill patients. Top. Relation between patients' care needs and caregivers' psychosocial burdens. White bars indicate caregivers of patients with few care needs; striped bars indicate caregivers of patients with substantial care needs. *P = 0.01; **P = 0.001. **Bottom.** Relation between the empathy of patients' physicians and the psychosocial burdens of caretakers of patients with substantial care needs. *P = 0.001; *P = 0.005; **P = 0.005; **P = 0.005;

American persons required assistance with nursing care but only 27.8% of white persons and 16.1% of Hispanic persons required such assistance (P < 0.001). Similarly, 31.4% of patients 65 years of age and older required assistance with personal care needs but only 17.5% of patients younger than 65 years of age required such assistance (P < 0.001). Among patients whose yearly incomes were less than \$15 000, 38.4% required nursing care; however, only 23.5% of those with higher incomes required such care (P < 0.001).

In multivariate logistical analysis, four factors were independently associated with substantial care needs: poor physical function (odds ratio, 2.77 [95% CI, 2.32 to 3.32]); age 65 years or older (odds ratio, 1.95 [CI, 1.38 to 2.77]); fecal or urinary incontinence (odds ratio, 1.88 [CI, 1.33 to 2.63]); and income less than \$15 000 per year (odds ratio, 1.81 [CI, 1.29 to 2.54]). Other factors, such as sex, ethnicity, education, marital status, religion, pain, depressive symptoms, cancer, length of illness, hospitalization in the previous 6 months, and managed care insurance, were not independently associated with substantial need for assistance. Three factors were independently associated with unmet care

needs: substantial care needs (odds ratio, 4.93 [CI, 3.52 to 6.91]); female sex (odds ratio, 1.98 [CI, 1.34 to 2.93]), and African-American ethnicity (odds ratio, 2.37 [CI, 1.48 to 3.79]).

Burdens of Substantial Care Needs

Substantial need for care was strongly associated with economic and other burdens (Figure 2). Terminally ill patients with moderate or high care needs were significantly more likely than those with low care needs to report that "the cost of [their] illness and medical care was a moderate or great economic hardship" for their family (44.9% compared with 35.3%; difference, 9.6 percentage points [CI, 3.1 to 16.1 percentage points]; P = 0.005); that 10% of their household income was spent on health care costs other than health insurance premiums (28.0%)compared with 17.0%; difference, 11.0 percentage points [CI, 4.8 to 17.1 percentage points]; $P \le 0.001$); and that they or their families had to sell assets, take out a loan or mortgage, or obtain an additional job to pay for health care costs (16.3% compared with 10.2%; difference, 6.1 percentage points [CI, 1.4 to 10.6 percentage points]; P = 0.004). Among patients requiring substantial assistance, 14.9% had seriously thought about or discussed euthanasia or physician-assisted suicide; however, only 8.2% of patients with few care needs had done so (P = 0.001).

Similarly, caregivers of patients with substantial care needs were significantly more likely than caregivers of patients with low care needs to have depressive symptoms (31.4% compared with 24.8%; difference, 6.6 percentage points [CI, 0.4 to 12.8 percentage points]; P = 0.01) and to report that their role as caregiver was "interfering with [their] family or personal life" (35.6% compared with 24.3%; difference, 11.3 percentage points [CI, 5.0 to 17.7 percentage points]; P = 0.001) (Figure 3).

Interventions To Ameliorate the Burdens of Care Needs

Caregivers of patients with substantial needs who reported that the physicians they dealt with listened to "the needs and opinions [of the caregiver] about the patient's illness or medical treatment" were significantly less likely to be depressed than caregivers who dealt with physicians who did not listen (27.6% compared with 42.0%; difference, 14.4 percentage points [CI, 2.5 to 26.3 percentage points]; P = 0.005) and to report that their role as caregiver interfered with their personal lives (31.5% compared with 47.7%; difference, 16.2 percentage points [CI, 4.1 to 28.4 percentage points]; P = 0.015) (Figure 3).

Discussion

Our study suggests a model that illuminates the previously unknown mechanism by which terminally ill patients and their families experience economic, psychosocial, and other burdens (Figure 4). Although the data presented here cannot prove cau-

sality, a plausible model based on the data suggests that terminally ill patients with physical symptoms experience substantial care requirements and, in turn, economic and other burdens.

The model generalizes the results of previous work that was limited to patients with cancer and applies them to patients with all terminal illnesses; it indicates that poor physical function, incontinence, older age, and low income are associated with greater care needs (4, 25, 26). More important, the model provides a plausible and coherent explanation of data from SUPPORT (7) and other studies (4), which indicate that physical functioning status and low income are associated with economic burdens: Economic hardships arise from the high care needs of terminally ill patients. Similarly, the model provides an explanation for previous data (1-6, 8, 9) that document the psychosocial burdens, such as depression, experienced by caregivers of terminally ill patients: The need to provide substantial assistance to dying patients generates psychosocial stresses on the caregivers.

However, the underlying factors that are associated with significant care needs and economic burdens in this model—older age, low income, poor physical function, and incontinence—are not readily modifiable or amenable to medical interventions. There is no way to change a patient's age, and no interventions can reliably and effectively improve physical function or prevent incontinence. This may severely limit or make more remote the possibility of alleviating economic and other burdens on terminally ill patients and their families. The only interventions that may be able to reduce burdens will probably be directed at attending to patients' care needs. Implementing interventions that provide as-



Figure 4. A model explaining a mechanism for economic and other burdens that terminal illness places on patients and caregivers.

sistance for patients' needs without imposing additional cost or effort on the caregiver may be the best way to ease the economic burdens of terminal illness. Additional hospice or home care services, especially unskilled home care services, may be useful only if they do not impose additional costs through high copayments. Unskilled care is frequently not considered a covered health benefit but may help address many care needs that are generated by poor physical function and incontinence, such as transportation, homemaking, and personal care. By performing these services, unskilled caregivers can provide relief for primary caregivers, allowing them to offer emotional and other support to the patient.

It is important to note that our data suggest a mechanism to ameliorate some of the psychosocial burdens on caregivers without requiring additional health care resources. It seems that physicians can reduce caregivers' depression simply by listening well. One effective way to improve physicians' empathy and ability to listen to patients and caregivers may be the implementation of more formalized and structured instruction during medical school, internships, and residency training.

Previous surveys of physicians who have received requests for euthanasia or physician-assisted suicide indicate that patients' fear of being a burden is a primary motivation for such inquiries (27, 28). Our data indicate a link between patients' reports of substantial care needs and consideration of euthanasia or physician-assisted suicide.

Our study has several limitations. First, our patient sample may be biased because physicians may have selectively referred patients who had fewer symptoms and problems. However, other studies of dying patients have required the consent of patients' physicians because of the sensitivity of interviewing terminally ill patients (7, 20, 22, 29). It is important to note that this bias did not seem to be considerable in these studies. The characteristics of the patients in our study mirror those seen in the U.S. population and in SUPPORT. Furthermore, physicians did not exclude patients who were experiencing substantial pain, functional debility, incontinence, depression, or care needs. In addition, physicians who referred patients did not know the hypotheses of our study and could not have anticipated the kinds of analyses of care needs that would be performed.

Second, 21% of the referred patients (310 of 1472) died or became mentally incapacitated before being interviewed. Patients with only days to live may have different needs and characteristics than terminally ill patients with a few months to live.

Third, more than 50% of the patients in our study had cancer and 23% of decedents die of can-

cer. This is not unusual because cancer is the leading cause of predictable deaths (13, 30). Deaths from heart disease, stroke, and other diseases are often sudden or occur after years of exacerbations and recoveries. Physicians may be more comfortable identifying patients with cancer as terminally ill. Consequently, our patient sample probably accurately reflects the attitudes and needs of patients who are known to be dying and situations in which interventions can facilitate a "good death" (13, 30).

Our study suggests that substantial care needs are a key mechanism that generate economic and psychosocial burdens on terminally ill patients, their families, and their caregivers. It also suggests that empathetic physicians who listen to patients and caregivers can reduce some of the burdens on caregivers. Training physicians to listen and increasing coverage of additional home care services—especially unskilled assistance—without increasing patients' and families' expenses could effectively relieve economic and other burdens.

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