

recommended that future studies of this type develop procedures to elicit mechanisms of decision making and situational variables (as well as use of physicians outside the dispensary).

In our previous paper we discussed the labeling of high risk workers that was a consequence of the establishment of the pallet plant. We see this trend again in our examination of dispensary visits for vague symptoms. Clearly the pallet plant workers were not using the dispensary for vague or non-existent disorders any more than other workers were. They were incorrectly perceived as dispensary abusers and labeled malingerers.

References

1. Kasl, S. V., and Cobb, S.: Health behavior, illness behavior. I. Health and illness behavior. *Arch Environ Health* 12: 246-266 (1966).
2. Koos, E.: *The health of Regionville*. Columbia University Press, New York, 1954.
3. Zola, I. K.: Culture and symptoms: an analysis of patients presenting complaints. *Am Sociol Rev* 31: 615-630 (1966).
4. Jaco, E. G., editor: *Patients, physicians and illness: a sourcebook in behavioral science and health*. The Free Press, New York, 1979.
5. Hetherington, R. W., and Hopkins, C. E.: Symptom sensitivity: its social and cultural correlates. *Health Serv Res* 4: 63-75 (1969).
6. Anderson, R., et al.: Perceptions of and response to symptoms of illness in Sweden and the United States. *Med Care* 6: 18-30 (1968).
7. Bursten, B., and D'Esposito, R.: The obligation to remain sick. *Arch Gen Psychiatry* 12: 402-407 (1965).
8. Tessler, R., Mechanic, D., and Dimond, M.: The effect of psychological distress on physician utilization: a prospective study. *J Health Soc Behav* 17: 353-364 (1976).
9. Mechanic, D., and Volkart, E. H.: Stress, illness behavior, and the sick role. *Am Sociol Rev* 26: 51-58 (1961).

10. Parsons, T.: *The social system*. The Free Press, New York, 1964.
11. Arluke, A., Kennedy, L., and Kessler, R. C.: Reexamining the sick-role concept: an empirical assessment. *J Health Soc Behav* 20: 30-36 (1979).
12. Kassebaum, G. G., and Baumann, B. O.: Dimensions of the sick role in chronic illness. *J Health Hum Behav* 6: 16-27 (1965).
13. Lipman, A., and Sterne, R. S.: Aging in the United States: Ascription of a terminal sick role. *Sociology Soc Res* 53: 194-203. (1969).
14. Chalfant, H. P., and Kurtz, R. A.: Alcoholics and the sick role: assessments by social workers. *J Health Soc Behav* 12: 66-72 (1971).
15. Baric, L.: Recognition of the "at-risk" role—a means to influence health behaviour. *Int J Health Educ* 12: 24-34 (1969).
16. Banks, F. R., and Keller, M. D.: Symptom experience and health action. *Med Care* 9: 498-502 (1971).
17. Apple, D.: How laymen define illness. *J Health Hum Behav* 1: 219-225 (1960).
18. Suls, J., and Mullen, B.: Life events, perceived control and illness: the role of uncertainty. *J Human Stress* 7: 30-34 (1981).
19. Sands, R. G., Newby, L. G., and Greenberg, R. A.: Labeling of health risk in industrial settings. *J Appl Behav Sci* 17: 359-374 (1981).
20. American Psychiatric Association: *Diagnostic and statistical manual of mental disorders (DSM-III)*. Author, Washington, DC, 1980.
21. Shuval, J. T., Antonovsky, A., and Davies, A. M.: Illness: a mechanism for coping with failure. *Soc Sci Med* 7: 259-265 (1973).
22. Fields, M. G.: *Doctor and patient in Soviet Russia*. Harvard University Press, Cambridge, 1957, chap. 9.
23. Waitzkin, H.: Latent functions of the sick role in various institutional settings. *Soc Sci Med* 5, 1971, (a) pp. 45-71; (b) p. 48.
24. Bradley, J. U.: *Distribution-free statistical tests*. Prentice Hall, Englewood Cliffs, NJ, 1968.
25. Wilcoxon, F., and Wilcoxon, R. A.: *Some rapid approximate statistical procedures*. Lederle Laboratories, Pearl River, NY, 1964.

Terminal Care Preferences: Hospice Placement and Severity of Disease

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Synopsis

National Hospice Study data for 1981-82 were used to predict the location of care for terminal cancer patients. Sites of care were conventional care in hospitals, hospital-based hospice care, and hospice care in the home. Subjects were terminal cancer patients with a prognosis of less than 6 months of life who were attended by a primary concerned person. There were 1,732 patients 18-99 years old—293 conventional care, 612 hospital-based hospice care, and 827 hospice home care patients.

Data sources were the patient, the primary concerned person, the family, and the medical record. Data were obtained at initial interview for the study, 1-week followup, reassessment every 2 weeks, and bereavement interviews. Information was grouped in the following categories: patient functional status, patient psychological outlook, symptomatology, medical condition, and characteristics of the primary concerned person and family.

Conclusions were reached by univariate and multivariate analysis. First, a progression of functional disability was found to exist among care sites, from hospice home care for the least dis-

abled to hospital-based hospice care to conventional care for patients with the greatest disabilities. The location of care was best explained by the patient's functional capacity. Second, the location of care was found to be poorly explained by extent of organ involvement or specific symptoms. Third, the primary concerned persons of patients under hospice home care experienced more stress but reacted no differently when compared with primary concerned persons at other care sites. Fourth, patients under hospice home care survived the longest and reported greater family closeness than other care groups.

THE HOSPICE CONCEPT WAS PIONEERED in Britain in the late 1960s. Since 1974, interest in providing hospice care has grown rapidly in the United States, and currently there are more than 1,200 functioning hospices in this country (1). Hospice philosophy focuses on palliative and supportive care and is especially appropriate for patients whose terminal status can be forecast and for patients who wish to die at home (2).

Public recognition of the availability of hospice care and the belief that hospice expenditures may be less costly than conventional care led to the 1981-82 National Hospice Study (NHS). Results indicated that the cost of terminal care provided by hospices was less than that of conventional care and that the less time patients spent in hospital beds, whether under hospice or conventional care, the greater the savings (1,3-6). Concerns remain, however, about the appropriateness of the site of care for dying patients (7), especially if families are unwilling to accept the burden of caring for patients at home. Our study used a secondary analysis of NHS data in a followup sample to examine the choice of site of care more critically for terminally ill patients.

Little systematic study has been given to the type of care most likely to meet patients' needs for care based on the existing level of illness and the available social support system. However, both the extent of disease and the availability of support services may be important in determining the appropriate location of care and of death (8). An understanding of the severity of the illness is critical to assessing the need for alternative health care services and to comparing medical care costs accurately (9-13). Many associated variables must

be accounted for, because no single indicator can serve as the criterion for assessment of the severity of the illness. Data collected by the NHS include information about the patients' functional ability, symptoms of illness, family support, and psychological outlook. As a result, it is possible to explore the impact of terminal cancer on the patient and support system in terms of the severity of the problem as related to the choice of care site.

Our hypothesis was that patients with the more severe illness (functionally and socially dependent) would choose conventional care in a hospital, the least ill patients would choose hospice care in their homes, and intermediately ill patients would choose hospital-based hospice care.

Materials and Methods

With Federal funding, a hospice demonstration project, the National Hospice Study, was initiated for Medicare patients in 14 localities nationwide to study the cost effectiveness of hospice care (14). Patients were not randomized, but they were allowed to select their own hospice or conventional care programs for terminal treatment. All services, including continuous care at home, were fully reimbursed by Medicare. Data used in our secondary analysis were derived from the followup sample of patients in the larger project.

Each patient in the study was required to have a primary concerned person, although common residence was not required. Primary concerned persons coordinated home services for patients. Entry criteria for patients included a prognosis of less than 6 months of life. Hospice subjects were

Figure 1. Significance¹ and direction of differences in functional status of terminal cancer patients, by site of care

Variables	Directionality ²
<i>Significant</i>	
Katz ADL (Activities of Daily Living) disability, use of intravenous support systems and catheters, oxygen use, ostomy care.	CC > HB > HC ³
Length of stay, education, age, married, Karnofsky functional status.	HC > HB > CC
<i>Not significant</i>	
Sex.	...

¹ Significant at $P < .05$.

² CC = conventional care, HB = hospital-based hospice care, HC = hospice home care.

³ Example: Patients receiving conventional care were more disabled according to the modified ADL scale of Katz than patients receiving hospital-based hospice care, who were more disabled than patients receiving hospice home care.

family, and medical records of the patient (16). There were 293 conventional care patients, 612 hospital-based hospice patients, and 827 hospice home care patients. Patients were between 18 and 99 years of age.

For the secondary analysis, the large number of patient variables available for analysis were grouped into four conceptual categories: patient functional status, patient psychological outlook and symptom reports, factors related to patients' medical conditions, and characteristics of the primary concerned person and family. The differences between care sites were assessed for patient variables that described the extent of functional and social dependence with univariate analysis of variance. Variables that significantly differentiated the groups were included in a discriminant function analysis in order to examine the relative contribution of each variable to site of care.

Results

Characteristics of the population studied are summarized in the table. Results of the univariate analysis of site of care with respect to the patient's functional status, psychological outlook and symptomatology, and medical condition, and the characteristics of the primary concerned person and family are shown in figures 1-5.

Patients receiving conventional care were more disabled than other patients according to the modified ADL (Activities for Daily Living) Scale of Katz (16) and the Karnofsky Performance Status Scale (15). Conventional care patients used more intravenous support systems and catheters (fig. 1). Hospice home care patients survived longer and were older and more often married than conventional care patients.

Patients under hospice home care lost more weight, had a greater appetite change, and had more cold sweats than patients receiving conventional care, but were calmer and happier and less lonely, frightened, and hopeless (fig. 2). In terms of those characteristics, patients receiving hospital-based hospice care resembled those under conventional care more than patients under hospice home care. No significant differences among groups were found regarding quality of life, level of awareness, and therapy for depression.

There were no consistent differences in extent of organ involvement with cancer among the different sites of care (fig. 3).

Compared with the conventional care group, hospice home care patients and their primary

Characteristics of terminal cancer patients at 3 different sites of care, using the secondary analysis of National Hospice Study data

Patient characteristic	Conventional care (N = 293)	Hospital-based hospice care (N = 612)	Hospice home care (N = 827)	Total study sample (N = 1,732)
Mean age, years ...	61.7	65.4	64.0	64.1
Sex:				
Males, percent ...	47	48	49	48
Females, percent ..	53	52	51	52
Live alone, percent .	17	16	7	12
Primary concerned persons' age, years	53.9	57.9	48.5	57.5

identified on admission to hospice care, and 4 percent refused to participate. Hospitalized terminally ill cancer patients who had Karnofsky functional index (15) scores of less than 50 percent were solicited to become members of the conventional care group; 20 percent refused to participate in the study.

Length of stay or survival was defined as the period from intake to the study to death or up to 7 months. Data were gathered in an initial interview, a followup interview 7 days later, subsequent biweekly followup interviews, and a bereavement interview with the primary concerned person 3-4 months after death. Information was gathered from the patient, primary concerned person, the

Figure 2. Significance¹ and direction of differences of patients' psychological outlooks and symptomatology by site of care

Variables	Directionality ²
<i>Significant</i>	
Weight loss, appetite change, need to be needed, felt calm and happy.	HC > HB > CC ³
Felt lonely, frightened, apathetic, hopeless.	CC > HB > HC
Cold sweats, self-strength.	HC > CC > HB
<i>Not significant</i>	
Difficulty sleeping, quality of life, level of awareness, religiosity, felt well most of the time, treatment for depression-anxiety.	...

¹ Significant at $P < .05$.

² CC = conventional care, HB = hospital-based hospice care, HC = hospice home care.

³ Example: Patients receiving hospice home care lost more weight than those receiving hospital-based hospice care, who lost more than those receiving conventional care.

Figure 3. Significance¹ and direction of differences in patients' medical conditions, by site of care

Variables	Directionality ²
<i>Significant</i>	
Liver and lymphatic involvement, pleural and peritoneal effusions.	CC > HB > HC ³
Obstruction present, other acute conditions.	HC > HB > CC
Other chronic condition.	HC > CC > HB
<i>Not significant</i>	
Extent of disease at diagnosis, brain and other sites of involvement, initial and subsequent treatment, bone marrow involvement, presence of metastases.	...

¹ Significant at $P < .05$.

² CC = conventional care, HB = hospital-based hospice care, HC = hospice home care.

³ Example: In patients receiving conventional care there was more liver involvement than in patients receiving hospital-based hospice care, who experienced more than those receiving hospice home care.

concerned persons were closer and reported being happier despite more burdensome patients and more stress and greater time commitment and loss of income (fig. 4). Primary concerned persons of patients under hospice home care reported being able to depend on a greater number of people for help. Conventional care patients were more likely than patients in the other care groups to live alone; the characteristics of families and primary concerned persons of hospital-based hospice patients were between those of the other two groups. There were no significant differences among groups with respect to demographic variables, family income, or evidence of psychological decompensation in primary concerned persons.

A multivariate analysis revealed a significant effect for site of care ($F [50,3140] = 3.68, P < .001$), based on the set of variables related to the patient's functional ability, age, and characteristics of the primary concerned person (fig. 5). These relationships were unchanged when age and length of stay among the groups were controlled.

Discussion

Several trends are suggested by our analysis. First, the location of care correlates best with the

Figure 4. Significance¹ and direction of differences in characteristics of primary care person (PCP) and family, by site of care

Variables	Directionality ²
<i>Significant</i>	
Family closeness; PCP saw patient daily; PCP's age, education, employment; PCP's obligation for patient care decreases (leisure, worktime, PCP health, income, ability to respond to needs of others and self); PCP happiness.	HC > HB > CC ³
Patient lived alone.	CC > HC > HC
<i>Not significant</i>	
Family income; friends of patient helpful; PCP's sex, race, religiosity, health, living arrangement, loss of significant others, relationship to patient; PCP was depressed, fearful.	...

¹ Significant at $P < .05$.

² CC = conventional care, HB = hospital-based hospice care, HC = hospice home care.

³ Example: Families of patients receiving hospice home care were closer than families of patients receiving hospital-based hospice care, who were closer than families of patients receiving conventional care.

Figure 5. Multivariate analysis of characteristics of 1,732 terminal cancer patients, by site of care

Conceptual category	Significant variables ¹	Directionality ²
Patient functional status.	Katz ADL disability	CC > HB > HC ³
	Karnofsky performance status	HC > HB > CC
	Length of stay	HC > HB > CC
Characteristics of primary concerned person (PCP) and family.	Age	HB > HC > CC
	PCP's patient obligation decreases (worktime, ability to respond to needs of others and self).	HC > HB > CC
	Family closeness	HC > HB > CC
	Number of family members and friends helping.	HC > HB > CC
Patient's outlook and symptomatology.	None	...
Patient's medical condition	None	...

¹ Significant at $P < .05$.

² CC = conventional care, HB = hospital-based hospice care, HC = hospice home care.

³ Example: Patients under conventional care had greater Katz ADL disability than patients under hospital-based hospice care, who had greater Katz ADL disability than patients under hospice home care.

patient's functional level. The worse the ADL disability and the more medical appliances that are needed (such as intravenous support systems and catheters), the more likely it is that patients will select conventional care, where more technologically sophisticated equipment or support is available. There was a progression of increasing functional disability, from hospice home care to inpatient hospice care to conventional care. Second, the location of care is poorly explained by the extent of organ involvement or specific patient symptomatology. Although some medical conditions and symptoms achieved univariate significance, they did not contribute to the overall effect of site of care. Third, despite the fact that primary concerned persons for the hospice home care group had more direct care responsibility and bore greater emotional and financial burdens as a result of their experiences, there were no differences in the psychological outlook of primary concerned persons or reactions to stress among the groups. This finding suggests that primary concerned persons for the home-based hospice group may be especially capable and resilient. Fourth, patients receiving hospice home care had the longest survival and reported an increase in family closeness during the course of the illness.

The progression in degree of functional dependency from hospice home care to hospital-based hospice care to conventional care among these patients suggests differences in care provided at different sites and that patients may select sites for reasons related to their functional dependency. Because of the methodologic problems inherent in the National Hospice Study (lack of randomization of patient selection and unavailability of all types

of hospice care in the same locality), it is difficult to be more conclusive given this data set. Individual site characteristics that may have influenced choice of location of care were not available for analysis. A comparison restricted to hospital-based hospice and hospice home care in the same locality with the same data set, however, revealed greater functional dependency among hospital-based hospice patients, supporting our more global hypothesis (17).

The patient's functional status, a global measure of disability, may be related to severity of disease (18), especially when patients have become ill enough to consider hospice care. Functional status has been suggested to represent the final common denominator for chronic disease states (19,20). Functional status has been related to survival after admission to a nursing home (21-24), a long-term geriatric unit (25), and after retirement (26). In the present study, ADL disability was an important predictor of site of care and may represent demand for level of care.

Choice of care site is not completely explained by the patient's functional status, however. There is generally a poor correlation between severity of illness and use of home health services, and it is uncertain whether a trend for less aggressive care of the older, sicker elderly may explain this finding (27). Use of medical care is poorly explained by reimbursement mechanisms, home health care availability, numbers of health care professionals, or availability of institutional care services (28). The amount of support available to the patient's family, however, may affect the choice of care site. It is those patients who have less extensive social support who are cared for in institutions. It

is curious that in our study we found patients in the home-based and hospital-based hospice groups to be older than patients receiving conventional care. Older persons would be expected to have fewer remaining social supports. Other researchers reported a younger population than we found among home-based hospice patients (29). The NHS requirement of a primary concerned person for each study participant may have affected the age distribution of the demonstration's hospice patients with respect to the general population. Controlling for age differences between care groups, however, did not affect the relationships of variables to the choice of care. It is important to consider available social support in order to classify patients and to place them according to need in appropriate levels of care (30-32).

Home hospice care is not a panacea for treatment of the elderly with chronic or terminal disease. We need both good home services and good institutional care alternatives for humane and effective care. Deciding how to use these alternative resources most effectively will take considerable additional thought and inquiry.

References

1. Kane, R. L., et al.: A randomized controlled trial of hospice care. *Lancet* No. 8382: 890-894, Apr. 21, 1984.
2. Groth-Juncker, A., and McCusker, J.: Where do elderly patients prefer to die? Place of death and patient characteristics of 100 elderly patients under the care of a home health care team. *J Am Geriatr Soc* 31: 457-461 (1983).
3. Greer, D. S., et al.: National hospice study analysis plan. *J Chron Dis* 36: 737-780 (1983)
4. Mor, V., and Birnbaum, H.: Medicare legislation for hospice care: implications of national hospice study data. *Health Aff* 2: 80-90 (1983).
5. Birnbaum, H. G., and Kidder, D.: What does hospice cost? *Am J Public Health* 74: 689-697 (1984).
6. Mor, V., and Kidder, D.: Cost savings in hospice: final results of the National Hospice Study. *Health Services Res* 2: 407-422 (1985).
7. Wade, D. I.: Augmented home nursing as an alternative to hospital care for chronic elderly invalids [letter to editor]. *Br Med J* 284: 739, Mar. 6, 1982.
8. Mor, V., and Hiris, J.: Determinants of site of death among hospice cancer patients. *J Health Soc Behav* 24: 375-385 (1983).
9. Cluff, L.: Chronic disease, function, and the quality of care. *J Chron Dis* 34: 299-304 (1981).
10. Katz, S., et al.: Active life expectancy. *N Engl J Med* 309: 1218-1224, Nov. 17, 1983.
11. Linn, M. W., and Linn, B. S.: The rapid disability rating scale-2. *J Am Geriatr Soc* 30: 378-382 (1982).
12. Kaplan, R. M., Bush, J. W., and Berry, C. C.: Health status index. Category rating versus magnitude estimation for measuring levels of well-being. *Med Care* 17: 501-506

- (1979).
13. Horn, S. D., et al.: Interhospital differences in severity of illness. Problems for prospective payment based on diagnosis-related groups. *N Engl J Med* 313: 20-24, July 4, 1985.
14. Greer, D. S., et al.: An alternative in terminal care: results of the National Hospice Study. *J Chron Dis* 39: 9-26 (1986).
15. Karnofsky, D. A. Abelman, W. H., Craver, L. F., and Burchenal, S. H.: The use of the nitrogen mustards in the palliative treatment of carcinoma with particular reference to bronchogenic carcinoma. *Cancer* 1: 634-656 (1948).
16. Katz, S., Downs, T. D., Cash, H. R., and Grotz, R. C.: Progress in development of the index of ADL. *Gerontologist* 10: 20-30 (1970).
17. Mor, V., Wachtel, T. J., and Kidder, D.: Patient predictors of hospice choice: hospital versus home care based programs. *Med Care* 23: 1115-1119 (1986).
18. Charlton, J.R.H., Patrick, D. L., and Peach, H.: Use of multivariate measures of disability in health surveys. *J Epidemiol Community Health* 37: 296-304 (1983).
19. Mor, V.: The Karnofsky performance status scale: a report from the National Hospice Study. Brown University Program in Medicine, Center for Health Care Research, Providence, RI, June 1984.
20. Katz, S., et al.: Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *JAMA* 185: 914-919, Sept. 21, 1963.
21. Goldfarb, A. I., Fisch, M., and Gerber, I. E.: Predictors of mortality in the institutionalized aged. *Dis Nerv System* 27: 21-29 (1966).
22. Goldfarb, A. I.: Predicting mortality in the institutionalized aged. *Arch Gen Psychiatry* 21: 172-176 (1969).
23. Donaldson, L. J., Clayton, D. G., and Clarke, M.: The elderly in residential care: mortality in relation to functional capacity. *J Epidemiol Community Health* 34: 96-101 (1980).
24. Lichtenstein, M. J., Federspiel, C. F., and Schaffner, W.: Factors associated with early demise in nursing home residents: a case control study. *J Am Geriatr Soc* 33: 315-319 (1985).
25. Rubenstein, L. Z., et al.: The Sepulveda VA geriatric evaluation unit: data on four-year outcomes and predictors of improved patient outcomes. *J Am Geriatr Soc* 32: 503-512 (1984).
26. Chirikos, T. N., and Nestel, G.: Longitudinal analysis of functional disabilities in older men. *J Gerontol* 40: 426-433 (1985).
27. Shapiro, E.: Impending death and the use of hospitals by the elderly. *J Am Geriatr Soc* 31: 348-351 (1983).
28. Hammond, J.: Analysis of county-level data concerning the use of Medicare home health benefits. *Public Health Rep* 100: 48-55, January-February 1985.
29. McCusker, J.: The use of home care in terminal cancer. *Am J Prev Med* 1: 42-52 (1985).
30. Doty, P.: Can home and community-based services provide lower cost alternatives to nursing homes? Working paper. Health Care Financing Administration, Office of Policy Analysis, Washington, DC, December 1984.
31. Adams, C. E.: The need for patient assessment. *J Tenn Med Assoc* 77: 32-33 (1984).
32. Kane, R. L., et al.: Predicting the outcome of nursing home patients. *Gerontologist* 23: 200-206 (1983).