Long-term Care Preferences of Hospitalized Persons with AIDS

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Objective: *To determine in a cohort of hospitalized persons with AIDS: 1) their preferences for various postdischarge long-term care settings, 2) the postdischarge settings recommended by primary care providers (doctors, nurses, and social workers), and 3) the impact of these views on the resulting discharge dispositions.*
Design: *Prospective cohort study.*
Setting: *Medical wards of five Seattle tertiary care hospitals.*
Participants: *120 consecutive hospitalized persons with AIDS and their primary care providers.*
Measurements and main results: *Although 70 (58%) of the patients found care in an AIDS long-term care facility acceptable, 87 (73%) preferred home care. Thirty-eight (32%) of the cohort were appropriate for long-term care after hospitalization, according to primary care providers. Eleven of the 38 patients deemed appropriate for long-term care were discharged to long-term care settings; among these, three had preferred home care. Likelihood of discharge to long-term care settings increased if patients found it acceptable (OR = 7.1; 95% CI = 3.2, 15.5), if they did not prefer home care (OR = 7.7; 95% CI = 4.7, 13.5), and if providers judged them to be appropriate for long-term care (OR = 29; 95% CI = 13, 64). In unstructured interviews, availability of emotional and medical support and privacy emerged as important factors to persons with AIDS considering long-term care.*
Conclusions: *Hospitalized persons with AIDS willingly express their desires for various postdischarge care settings. A majority find long-term care in AIDS facilities acceptable, although they generally prefer home care. Discharge disposition is associated with acceptability, preference, and appropriateness for long-term care.*
Key words: *AIDS; acceptability of health care; patient preferences; long-term care; discharge planning.* J GEN INTERN MED 1991;6:524–528.

AS THE TREATMENTS for the opportunistic illnesses constituting AIDS improve and as clinical manifestations of HIV infection are forestalled with antiviral therapy, AIDS has come to represent a chronic illness similar to other catastrophic illnesses.[1,2] Treatments of the chronic complications of AIDS often do not require hospitalization, particularly if diagnostic tests are not needed.[3] Rather, care in nonhospital settings (home, nursing home, or hospice care) may be more desirable to some patients and their health care providers and may reduce the cost of care.[1-7]

As part of a prospective cohort study of hospitalized, acutely ill persons with AIDS,[8,9] we sought patient preferences for various long-term care options in the event that chronic, ongoing medical care would be necessary after their hospital stays. The opinions and preferences of such individuals regarding their own future care may differ from those previously described for patients in other demographic groups considering long-term care options (e.g., the elderly).[10,11] We hypothesized that the preferences of these AIDS patients would be reflected in their eventual discharge dispositions. We describe here the dynamic between patient acceptance of (and preferences for) long-term care settings, the judgments of their doctors, nurses, and social workers regarding the appropriate settings for post-hospital care, and actual eventual discharge dispositions in an American city with limited long-term care options for persons with AIDS.

METHODS

Settings

We recruited subjects at five large hospitals in Seattle: a municipal hospital caring primarily for indigent patients, two private hospitals, a Veterans Affairs (VA) hospital, and the hospital of a large health maintenance organization. These five hospitals care for about 80% of persons with AIDS requiring hospitalization in the Seattle metropolitan area, and about 60% of those in the state of Washington.[12]

Subjects

All study procedures conformed to guidelines of human subject review committees or institutional review boards of participating institutions and complied with Washington State AIDS Omnibus Legislation.[9] Study referrals were elicited from physicians, nurses, and social workers specialized in working with AIDS

Received from the University of Washington, Harborview Medical Center (WCM, TSI, RAD), and the AIDS Prevention Project, King County Department of Public Health (RWW), Seattle, Washington.

Presented in part at the Vth International Conference on AIDS, Montreal, Quebec, Canada, June 5, 1989. Also presented in part at the 14th annual meeting of the Society of General Internal Medicine, Seattle, Washington, May 1–3, 1991.

Supported in part by the Northwest Health Services Research and Development Field Program (Seattle VA Medical Center) and the Seattle/King County Department of Public Health, AIDS Prevention Project. Dr. McCormick was a fellow in the Robert Wood Johnson Clinical Scholars Program during this project.

The opinions stated herein are those of the authors and may not represent the views of the Robert Wood Johnson Foundation or the Department of Veterans Affairs.

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patients at the participating institutions. Written consent was obtained from the patient or patient advocate (first-degree relative, guardian, or person with durable power of attorney). All patients who met Centers for Disease Control (CDC) diagnostic criteria for AIDS[13] and who gave informed consent were enrolled consecutively during the eighth-month study period in 1988-1989. Of all the AIDS patients hospitalized on wards where the study was under way, 70% enrolled. No significant difference existed between nonenrollees and subjects in age, diagnosis, or disposition.[9]

Procedures

Once consent was obtained, we examined the medical records of and interviewed study subjects. In the case of incompetent subjects, proxy information was obtained from the person giving informed consent for the subject (17% of the cohort). Near the time of enrollment, persons with AIDS were asked, "If it were necessary, would a stay in a long-term care AIDS facility be acceptable to you after your stay in the hospital, relative to a longer stay in the hospital?" and "Would you prefer home care to ongoing care in a long-term care AIDS facility or hospital, *if it could be arranged?*" Patients were also asked to comment on general aspects of long-term care that would be important to them in the event that they required long-term care.

We obtained the judgments of primary care providers (physicians, nurses, and social workers) regarding the appropriateness of long-term care for each subject, after supplying a clear general description to allow for uniformity of concept among respondents (an existing six-bed special AIDS long-term care facility was used as an example in all questions).[8] Providers were told that, in general, "long-term care" included any facility that had skilled nursing and that accepted persons with AIDS, and that long-term care was for patients who: 1) no longer required the level of care available in an acute care setting, 2) could be cared for without risk in a less supervised setting with a lower caregiver-to-patient ratio, and 3) were not well enough to be discharged to their home. Caregivers then responded to the following question: "If a long-term care bed were available, could (*name of person with AIDS*) be transferred there as a substitute for further hospitalization, is further hospitalization necessary, or could care be accomplished at home?" Responses were solicited weekly while the subjects were hospitalized.

All judgments were made independently, that is, without the overt knowledge of the opinions of other caregivers. The a priori definition of "appropriate" was met if the physician and at least one other caregiver (nurse and/or social worker) independently stated at least two weeks in a row that the patient was appropriate for long-term care.[8] We followed all patients from enrollment until hospital discharge.

TABLE 1

General Characteristics of the Cohort ($n = 120$)

Age—mean ± SD (range)	35 ± 7 years (22-53 years)
Race	
White	104 (87%)
Black	8 (7%)
Asian	2 (2%)
Hispanic	4 (3%)
Native American	2 (2%)
Risk behavior	
Homosexual	94 (78%)
Intravenous drug use	4 (3%)
Both of the above	18 (15%)
Transfusions	1 (1%)
Unknown	3 (2%)
Diagnosis (admitting)	
Pneumocystis pneumonia	59 (49%)
Kaposi's sarcoma	7 (6%)
Toxoplasmosis	4 (3%)
Cytomegaloviral infection	9 (8%)
Candidal infection	4 (3%)
Mycobacterial infection	7 (6%)
Cryptococcosis	5 (4%)
Herpes infection	3 (2%)
Wasting syndrome	8 (7%)
Lymphoma (central nervous system)	3 (2%)
HIV dementia	11 (10%)
Length of illness (since AIDS diagnosis)—mean ± SD (range)	7 ± 9 months (0-48 months)
Length of hospital stay—mean ± SD (range)	15 ± 13 days (2-82 days)
Living situation	
Alone	45 (38%)
With others	75 (62%)
Insurance	
Medicaid or none	60 (50%)
Private insurer	60 (50%)
Impaired in ADLs*†	42 (35%)
Weight loss†‡	51 (42%)
Mini-Mental State Score < 24†§	21 (18%)

*ADLs = activities of daily living: bathing, eating, dressing, transferring, going to the toilet, and continence.

†For a detailed discussion of these measures, see: McCormick WC, Inui TS, Deyo RA, Wood, RW. Long-term care needs of hospitalized persons with AIDS: a prospective cohort study. J Gen Intern Med. 1991;6:27-34.

‡10% or more of their usual or normal weight in the past month.

§A score of 30 is normal cognition, and < 24 signifies dementia.

Analysis

Data were analyzed with the SPSS/PC+ statistical program (SPSS, Inc., Chicago, IL, 1990). Analyses included descriptive statistics, bivariate comparisons (chi-square test with Yates' corrections), and logistic regression. The Ethnograph© computer program (Qualis Research Associates, Littleton, CO, 1988) was used to code, tabulate, and count frequencies of comments obtained during unstructured interviews.

TABLE 2

Actual Discharge Dispositions of the Study Subjects ($n = 120$)

Home	86	(72%)
Home with home care	16	(13%)
Adult family home*	5	(4%)
Nursing home*	4	(3%)
Hospice*	2	(2%)
Died in hospital	7	(6%)

*Long-term care settings, total = 11 (9%).

TABLE 3

Discharge Disposition According to Appropriateness* for Long-term Care

Disposition at Discharge	Appropriate $n = 38$		Not Appropriate $n = 82$	
Home	14	(37%)	72	(88%)
Home with home care	8	(21%)	8	(10%)
Adult family home†	5	(13%)	0	(0%)
Nursing home†	4	(11%)	0	(0%)
Hospice†	2	(5%)	0	(0%)
Died in hospital	5	(13%)	2	(2%)

*Based on caregiver judgments.

†Long-term care facilities with skilled nursing accepting persons with AIDS.

Chi-square = 44, $p < 0.0001$.

In the patient interviews, comments were elicited from the subjects by two interviewers. Frequencies of the coded comments between these interviewers were similar (identical top five codes). Two physician ethnographers independently assigned codes to the comments. Agreement (same code or similar codes) between the physician ethnographers was 76%.

RESULTS

Descriptive characteristics of the study subjects (all males) can be found in Table 1. Seventy (58%) found long-term care acceptable as a possible discharge disposition or a substitute for hospital care. A larger proportion (87 patients, or 73%) stated they generally preferred home care to long-term care or hospital care, if it could be arranged. Using the definition of appropriateness previously described,[8] 38 of the 120 subjects (32%) were considered appropriate for long-term care by their providers. Discharge disposition for the entire cohort is outlined in Table 2 and stratified by appropriateness in Table 3.

The branching-tree diagram in Figure 1 further illustrates the relationship among patient acceptability of and preferences for long-term care settings, the judgments of primary care providers regarding appropriateness for long-term care, and the resulting eventual discharge disposition. Discharge disposition was highly correlated with acceptability of, preferences for, and appropriateness for long-term care using chi-square analysis (Table 4).

Odds ratios obtained using logistic regression are also found in Table 4. These ratios reflect the fact that if patients found long-term care acceptable, the odds of long-term care as an eventual discharge disposition were significantly increased (they were seven times more likely to be discharged to a long-term care facility than were patients who found long-term care unacceptable). This was also the case if they did not prefer home care (seven to eight times more likely) or were judged appropriate for long-term care by their providers (29 times more likely). These relationships were maintained whether or not the subjects who died in the hospital were included in the analysis. Multivariate logistic regression could not be performed due to multicollinearity and the small number of subjects in selected strata. However, it can be seen in Figure 1 that if subjects found long-term care acceptable and did not prefer home care and if providers felt long-term care was appropriate, such subjects in this cohort either were discharged to long-term care settings or died in the hospital prior to discharge. Only patients judged appropriate for long-term care were discharged to long-term care settings, although several appropriate patients also went home with or without home care. On the other hand, two patients who found long-term care acceptable but preferred home care were also discharged to long-term care settings, as was a patient who found long-term care unacceptable and preferred home care.

Content analysis of interview comments revealed that availability of support from loved ones and medical professionals, privacy, a home-like environment, camaraderie, independence, and access to medical care (in descending order of frequency) were among the factors important to the patients when considering long-term care settings. A frequent comment among patients was that while care in the AIDS long-term care facility was acceptable, they themselves did not currently need it (fifth most common code). The results of frequency analysis of coded comments can be found in Table 5.

DISCUSSION

Long-term care of persons with AIDS in nonhospital settings (skilled nursing facilities and home care) has assumed increasing importance for several reasons: limitations in hospital capacity,[6, 7] the high cost of hospitalization,[1, 2] the increasingly chronic nature of AIDS,[14] and patient and provider preferences for care outside hospitals.[4, 5] If long-term care options are scarce, discharge from the hospital may be delayed; social circumstances (such as homelessness) may be as important as medical conditions in causing prolonged hospitalization.[15, 16] Consequently, care in long-term care settings may be necessary or desirable for many hospitalized persons with AIDS.

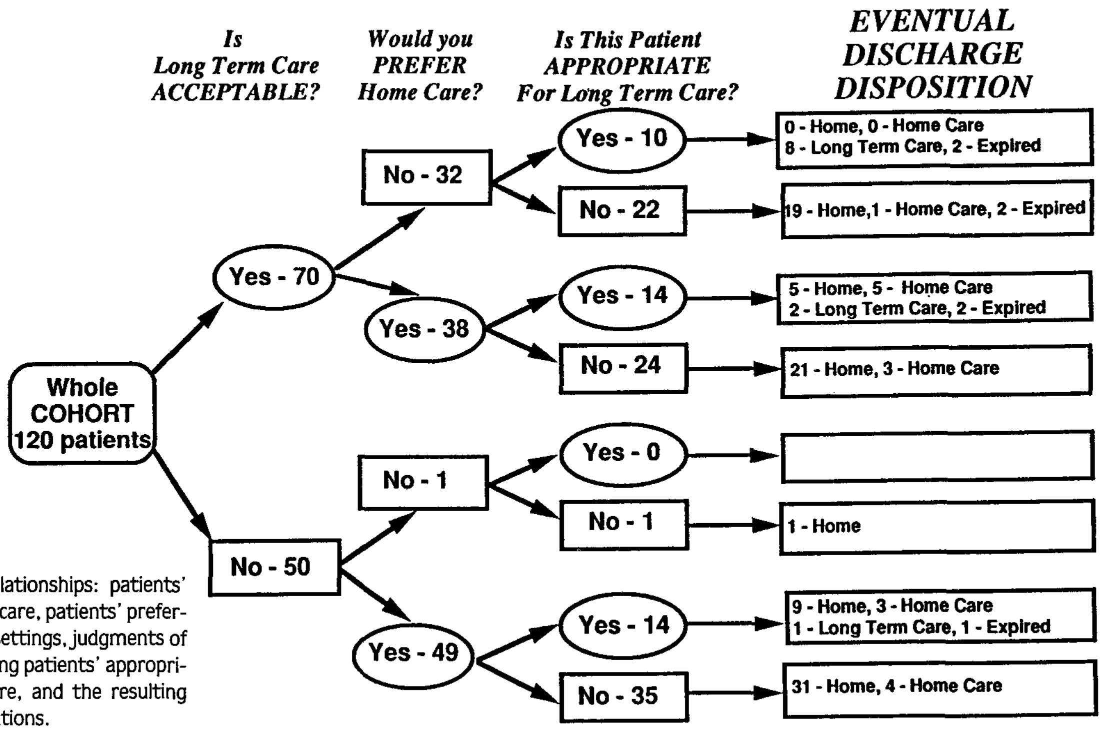

FIGURE 1. Interrelationships: patients' acceptability of long-term care, patients' preferences for long-term care settings, judgments of primary providers regarding patients' appropriateness for long-term care, and the resulting eventual discharge dispositions.

However, nursing home placement of persons with AIDS has been difficult due to heavy care needs (as well as differences in age and culture) compared with other nursing home patients, and due to the fact that the demand for nursing home beds often exceeds the supply (this was true even before the AIDS epidemic).[14, 17] Rango et al.[18] have estimated that nursing home care would be appropriate for a sixth to a third of all hospitalized persons with AIDS in New York City hospitals, and similar estimates have been made in San Francisco.[19] While these studies emphasize the need to increase the availability of long-term care facilities for persons with AIDS, the opinions of these patients regarding their care settings have remained obscure. If AIDS long-term care settings were preferred to ongoing hospitalization, patient satisfaction with care might be improved, and costs of care reduced, by expanding these facilities, especially if it were appropriate in the view of their physicians, nurses, and social workers.[4, 14]

Several investigators have studied long-term care acceptability in other populations of persons for whom the need may be imminent, that is, in the elderly.[10, 11] In a 1984 survey by the American Association of Retired Persons,[10] 80% of members preferred home care to nursing home care. Similarly, a large proportion of subjects in this cohort of AIDS patients preferred home care to long-term care or ongoing care in the hospital, if it could be arranged. Kulys[11] found that elderly persons in the Chicago area did not find nursing home care to be an acceptable option, although most expected to enter

TABLE 4

Discharge Disposition of the Study Subjects in Relation to Acceptability of, Preferences for, and Appropriateness for Long-term Care Settings

	Discharge Disposition*					
	Home	Long-term Care	χ^2	p	Odds Ratio	95% CI
Acceptability						
Acceptable	54	16	6.7	0.0095	7.1	3.2, 15.5
Not acceptable	48	2				
Preference						
Do not prefer home care	21	12	14.1	0.0002	7.7	4.7, 13.5
Prefer home care	81	6				
Appropriateness						
Appropriate	22	16	29.0	0.0001	29	13, 64
Not appropriate	80	2				

*Home (with or without home care) versus long-term care (any long-term care facility) or death.

TABLE 5

Areas of Concern to Hospitalized Persons with AIDS When Considering Long-term Care Settings*

Availability of support (from loved ones and medical professionals)
Privacy
Home-like environment
Atmosphere of camaraderie and community
"Acceptable, but I don't need it"
Maintenance of independence
Access to medical care
Access to recreational outlets
Nutritional support
Atmosphere of compassion
Ability to have guests/visitors
Maintenance of a sense of order through "rules of the house"
Ability to go outdoors/gardening

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*In descending order of frequency. Responses were obtained in unstructured, open-ended interviews.

one if they needed care. A majority of subjects in our cohort found care in AIDS long-term care facilities acceptable. This discrepancy may reflect the differences in age and culture between the elderly and the majority of persons with AIDS (in our population sample, predominantly young homosexual men) and differences in the contexts and settings in which questions were asked. Persons interviewed in these studies of the elderly were familiar with nursing homes because of contact with friends or relatives who had stayed in them. Similarly, many of the subjects in this study knew of the AIDS long-term care facility in Seattle and had helped care for friends who had stayed there.

The results of this study may not be directly applicable to other urban areas. The demographic characteristics, risk behavior prevalences, and disease courses of populations of persons with AIDS vary considerably across the country. Different results might have been obtained from ambulatory persons with AIDS who were feeling well at the time of the interview. We surveyed hospitalized persons with AIDS to enhance the validity of our findings; we believe that more valid comments can be elicited from ill individuals actually facing these decisions. Our conclusions should be generalized with caution and may be most applicable to cities with demographic characteristics and risk behavior prevalences similar to those of West Coast urban areas.

CONCLUSION

Persons with AIDS willingly express their desires for various posthospital care settings. A majority feel that an AIDS long-term care facility is an acceptable care setting. Patients prefer home care, however, whether they find long-term care acceptable or unacceptable and whether they are judged by their providers to be appropriate or inappropriate for long-term care. Expansion of the availability of intensive home care for persons with AIDS may be warranted in view of this. There is a strong correlation between appropriateness for, preference for, and acceptability of long-term care and eventual discharge disposition. Most of the hospitalized persons with AIDS in our study had specific ideas about what aspects of care they felt were important when considering long-term care. Their comments will be helpful to planners and administrators of long-term care facilities willing to care for persons with AIDS.

The authors express their gratitude to the professional staffs of the participating hospitals for their cooperation. They thank Carol deGroff, RN, for help with data gathering; Kayla Brodkin, MD, and David Grossman, MD, for help with ethnographic analysis; and Bruce Psaty, MD, PhD, for help with data analysis.

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