

Managing End-of-Life Care: Comparing the Experiences of Terminally Ill Patients in Managed Care and Fee for Service

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There have been no published empirical studies comparing the experiences of terminally ill patients in managed care organizations (MCOs) and those in fee for service (FFS). This investigation represents the first empirical study to systematically compare substantive outcomes between populations of terminally ill patients enrolled in MCO and FFS healthcare delivery systems. The investigators interviewed 988 patients whose physicians judged them to be terminally ill and 893 of their caregivers. Outcomes assessments were made in six domains: patient-physician relationship; access to care and use of health care; prevalence of symptoms; and planning for end-of-life care, care needs, and economic burdens.

Overall, the two populations of terminally ill patients were found to have comparable outcomes, but several significant differences were present. MCO patients were more likely than their FFS counterparts to use an inconvenient hospital ($P = .02$), spend more than 10% of their income on medical care ($P = .02$), and have been bedridden more than 50% of the time during the last 4 weeks of life ($P = .03$). Caregivers of MCO patients were as likely as the caregivers of FFS patients to report a substantial caregiving burden ($P = .59$). Despite concerns about the threats of MCOs to the physician-patient relationship, few differences in the quality of the relationship between the two cohorts were found. Finally, terminally ill patients in MCOs did not show better experiences than those in FFS on any outcome measure. Additional research is required to explore how

MCOs may improve upon the care available to dying patients. *J Am Geriatr Soc* 50:2077–2083, 2002.

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There is an intense debate over the quality of and satisfaction with the medical care provided in managed care settings and how it compares with that in fee-for-service (FFS) settings.^{1–5} Existing data suggest that managed care organizations (MCOs) achieve higher rates of preventive services, such as breast, cervical, and colorectal cancer screenings, and immunizations,^{6–8} than FFS and equivalent patient satisfaction in some areas,^{9–11} but many critics argue that managed care may be good for the healthy but bad for the sick.¹² They point to studies showing that older people, the chronically ill, those with severe mental illnesses, and Medicaid recipients have worse health outcomes when enrolled in MCOs.^{13–15} For instance, it is claimed that chronically ill Medicare patients have problems with access to medical services and that hospitalizations tend to be less frequent and shorter for these MCO enrollees.^{16,17} Some commentators argue that the lack of risk adjustment may deter MCOs from providing optimal care for seriously ill patients, who generally have high resource use.¹⁸

Some have voiced grave concern about the quality of care that terminally ill patients will receive in MCOs, especially because care of the patients is very costly (Peter Fox, personal communication).^{19–20} Others have suggested that MCOs may be able to provide better services to the severely and terminally ill because of their ability to coordinate care and provide case management.^{21–23} These concerns are becoming even more pressing as Medicare patients are encouraged to enroll in MCOs, making MCOs responsible for the care of a growing number of the terminally ill.^{24,25}

Despite these concerns, there is an almost total absence of data on the care of dying patients in MCOs. The one empirical study that included data on terminally ill patients in MCOs reported that dying patients used fewer unnecessary hospital services than those in FFS,²⁶ but, be-

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cause it used an incomplete MCO data set, some have questioned the reliability of its findings.²⁷

To provide data on the effect of managed care delivery systems on end-of-life care, this study compared the personal experiences of terminally ill patients in MCOs and FFS, evaluating differences in access to care, use of health services, financial burdens, symptoms, caregiving needs, end-of-life planning, and site of death.

METHODS

A detailed description of the study methodology has been reported elsewhere.^{28,29} The investigators opted to enroll participants from outpatient settings using physician determinations of terminal status for the following reasons. Many terminally ill patients are no longer admitted to hospitals and do not die in the hospital. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) found physician determination of patients' 6-month survival almost as accurate as formal medical criteria.³⁰ Finally, physicians do not use formal criteria to determine terminal status in routine practice such as hospice referrals.

Sampling

A multistage, cluster sampling strategy was used. The first stage in sampling was the selection of the study sites, metropolitan statistical areas (MSAs), representing different degrees of managed care penetration. Four MSAs with high penetration of managed care, one MSA with low penetration of managed care, and one rural county were randomly selected. The six sites were: Worcester, Massachusetts; St. Louis, Missouri; Tucson, Arizona; Birmingham, Alabama; Brooklyn, New York; and Mesa County, Colorado. The second sampling stage involved the selection of a random sample of physicians within each MSA. From lists provided by state boards of medical registration and state medical societies and membership lists from professional societies, physicians were randomly selected. Physicians were asked to identify patients who "have a significant illness (except human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS)) and a survival time of six months or less, in your opinion." Overall, 383 physicians referred patients.

The final stage of sampling involved contacting patients referred to the study. No patient or caregiver was paid to participate. Patients were eligible if they had any significant illness, excluding HIV/AIDS; had a prognosticated survival time of less than 6 months, as determined by their physician; spoke English; had no hearing difficulty; and were competent to arrange an interview time and place and to sign a consent form. Identified patients were sent a letter explaining the study along with a postage-paid "opt-out" card. Patients who did not return an opt-out card were contacted to arrange for an in-person interview at a site and time of their choosing. Physicians identified 1,472 patients, of whom 341 were ineligible (194 had died, 116 were mentally incapacitated, and 31 did not speak English or had hearing limitations). Of the 1,131 eligible patients, 119 returned the opt-out card, and 24 could not be located. Nine hundred eighty-eight patients were interviewed (response rate = 87.4%).

Caregiver Identification, Contact, and Recruitment

Patients were asked to identify their primary caregiver, specified as the family member, friend, or other person who provided the most assistance. Of the 988 patients, 70 reported they did not have caregivers, three caregivers did not speak English, and 22 refused to participate. Eight hundred ninety-three caregivers were interviewed (a response rate of 97.6%).

Survey Development

The patient and caregiver survey instruments were developed in conjunction with the Center for Survey Research at the University of Massachusetts, Boston, and the National Opinion Research Center, and guided by a previously outlined conceptual framework.³¹ The survey instruments were developed using the following steps: literature search; 15 focus groups; six in-depth interviews with terminally ill patients and caregivers; instrument creation; cognitive and behavioral pretesting; reliability assessment; and review by an expert panel. The survey instruments were piloted with 18 patients and 15 caregivers in Cleveland, Ohio, and Dallas, Texas.

The surveys examined health status and symptoms; social support; communication with health providers; personal and spiritual meaning; care needs and responsibilities; end-of-life care plans; economic burdens of care; sociodemographics; attitudes and plans regarding end-of-life care, euthanasia, and physician-assisted suicide; and stress of the interview.

Survey questions on symptoms were adapted from the Wisconsin brief pain inventory,³² Medical Outcomes Study (MOS) 36-item short form,³³ and the Eastern Cooperative Oncology Group performance measure;³⁴ and items on social supports were taken from the MOS Social Support Scale.³⁵ Using questions from Siegel et al.³⁶ and Rice et al.,³⁷ patients and caregivers were asked about care needs. Questions regarding healthcare expenditures were taken from Epstein et al.³⁸ Questions on advance care planning were adopted from Emanuel et al.³⁹ Additional questions on physician-patient communication, advance care planning, and economic burdens of care were newly developed and tested for this survey instrument.

Health Insurance Determination

To determine whether patients received care through MCOs or FFS, patients were asked to identify their primary insurance provider. This information was matched with the type of insurance reported by the referring physician. If the physician and patient did not identify the same insurance provider, the name of the company billed for the patient's care was used. A primary insurance provider was identified for 92.3% of patients (912/988). Managed care status was determined using a combination of the following criteria. The insurer was a known MCO, a capitated form of physician payment was used, there was a restricted network of physicians from which the patient could choose, and there was a state Medicaid program known to be an exclusively managed care Medicaid program.

Interview Process

Twenty-four interviewers from the National Opinion Research Center, specially trained to interview terminally ill

patients, conducted all interviews in person. Patients and caregivers were initially interviewed; caregivers of patients who died in the months subsequent to the initial interview were administered a postbereavement interview. Interviews were completed between March 1996 and June 1997.

Human Subjects Approval

The Harvard Medical School and Dana-Farber Cancer Institute's institutional review boards (IRBs) and the IRBs of 38 medical institutions in the six sites approved the protocol, letters, survey instruments, and consent documents.

Data Analysis

Caregiving need was determined from patient ratings of the amount of care that they needed in four areas, as previously reported.²⁹ Statistical analyses were performed to assess the association between insurance status and patient characteristics: chi-square tests for dichotomous outcomes, Mantel-Haenszel chi-square tests for ordered categorical outcomes, and *t* tests for continuous outcomes.⁴⁰ The association between insurance status and certain patient characteristics were examined using logistic regression models that controlled for older age, religion, race, diagnosis of heart disease, severity of illness (i.e., being bed-ridden more than 50% of the day), and site of recruitment because of significant differences between the two groups on these measures. All proportions reported were adjusted for differences associated with the above factors. With the observed distribution of patients in MCO and FFS plans, there is adequate power (power $\geq 80\%$, two-sided tests, $\alpha = 0.01$) to detect a difference of 0.26 standard deviations in the continuous outcomes and to detect differences in proportions of 50% versus 63% or of 10% versus 19%, which are clinically meaningful differences. To examine whether associations between the degree of MCO penetration and outcomes might differ among the six sites, the Breslow-day test for homogeneity of odds ratios was performed for key outcomes.

All proportions reported were adjusted for differences associated with older age, religion, race, diagnosis of heart disease, severity of illness (i.e., being bed-ridden more than 50% of the day), and site of recruitment.

RESULTS

Characteristics of the Terminally Ill Patients

Table 1 compares the sociodemographic characteristics of the 23.5% of patients enrolled in MCOs with the 74.8% of FFS patients (1.7% of patients lacked health insurance.) Patients in MCOs were slightly more likely to be younger (mean age 65.0 in MCOs vs 67.7 in FFS; $P = .03$) and less likely to be African American ($P = .04$) or Jewish ($P = .01$) (Table 1). MCOs were significantly less likely than FFSs to have patients with terminal heart disease and more likely to have patients with cancer, chronic obstructive pulmonary disease, or other terminal illnesses ($P < .001$). Although not statistically significant, more FFS than MCO patients reported being bed-bound greater than 50% of the time ($P = .06$). There were no differences between patients in MCOs and FFS in terms of sex, education, family income, or marital status.

Table 1. Comparison of the Demographic Characteristics of Terminally Ill Managed Care (MCO) and Fee-for-Service (FFS) Patients

Characteristic	MCO (n = 232)	FFS (n = 739)	P-value
Age*			.01
18–50	16.4	12.4	
51–64	35.5	22.6	
65–84	41.6	58.7	
≥ 85	6.5	6.3	
Sex			.07
Male	50.4	43.5	
Female	49.6	56.5	
Race*			.04
White	81.6	78.8	
Black	9.0	14.8	
Other	9.4	6.4	
Religion*			.01
Protestant	62.8	61.3	
Catholic	27.8	24.7	
Jewish	0.0	5.67	
Other	9.4	8.33	
Education			.92
$\leq 8^{\text{th}}$ grade	11.4	15.7	
Some high school	16.2	18.8	
High school graduate	31.4	26.8	
Some college	29.5	19.1	
College graduate	11.4	19.7	
Income			.23
$< \$15,000$	31.2	37.5	
$\$15,000$ – $24,999$	25.5	21.3	
$\$25,000$ – $\$49,000$	26.7	26.7	
$> \$50,000$	16.6	14.5	
Marital status			.37
Married	60.8	57.5	
Widowed	22.4	20.1	
Divorced	7.0	8.8	
Other	9.8	13.5	
Disease*			.00
Cancer	49.1	52.9	
Heart disease	12.3	20.4	
Other	38.6	26.7	
Site of residence*			.00
Worcester, MA	10.2	16.6	
St. Louis, MO	16.8	23.9	
Tucson, AZ	37.4	13.1	
Birmingham, AL	13.1	25.8	
Brooklyn, NY	1.9	15.6	
Mesa, CO	20.6	5.0	
Physical status*			.06
Bed-bound $> 50\%$ of the day	11.7	18.4	

*Covariates that were adjusted for in the multivariate analyses presented in the Results section. Adjustment for these covariates in the multivariate analyses was made to isolate differences in outcomes due to healthcare delivery settings (MCO vs FFS).

Symptoms of the Terminally Ill Patients

There were no significant differences in the prevalence of symptoms between the patients in MCOs and FFS. For instance, reported levels of pain were similar between the two populations, with 48.4% of MCO patients and 51.2% of

FFS patients reporting a moderate or great amount of pain ($P = .54$). Rates of shortness of breath after walking one block were also comparable between the two cohorts (74.8% of MCO patients vs 70.3% of FFS patients; $P = .28$). Both groups reported similar rates of depression (16.5% of MCO patients vs 15.1% of FFS patients; $P = .66$) and incontinence (32.2% of MCO patients vs 36.5% of FFS patients; $P = .32$).

Patient-Physician Relationship

Overall, there were no significant differences in the patient-physician relationship between the MCO and FFS patients. Both MCO and FFS patients reported extremely high levels of trust in their primary physician (98.7% of MCO patients versus 96.7% of FFS patients; $P = .15$). Of the MCO patients, 84.0% reported receiving clear and adequate information about their condition, compared with 84.7% of FFS patients ($P = .84$), and 24.0% of MCO patients reported receiving conflicting information from the healthcare team, compared with 27.9% of their FFS counterparts ($P = .34$). Most (98.2%) patients in MCOs reported that their physician acts as an advocate for them, helping them “through the medical system to get the medical care [they] need,” compared with 98.6% of FFS enrollees ($P = .67$). Of the MCO patients, 94.3% reported that their physician delivered bad news sensitively, as did 93.3% of FFS patients ($P = .64$). MCO patients were as likely as their FFS counterparts to report participating meaningfully in treatment decisions (97.5% vs 97.4%, respectively; $P = .92$). There was no statistically significant difference between the difficulty experienced in reaching their physician by telephone, with 13.8% of the MCO cohort and 12.0% of the FFS patients reporting such difficulty ($P = .53$).

Caregiver-Physician Communication

Of caregivers of the MCO patients, 12.5% received important information from nurses that had not been given by the primary physician, whereas 9.9% of FFS caregivers reported this ($P = .35$). Overall, 29.6% of the MCO caregivers had difficulty reaching the patient’s physician by telephone, compared with 24.3% of caregivers of FFS patients ($P = .20$).

Access and Use of Health Care Services

Figure 1 compares differences in access and use of health care. Although the percentages are quite small, patients enrolled in MCOs were significantly more likely to report using a hospital that was inconvenient (4.2% of MCO patients vs 1.9% of FFS patients; $P = .02$). Of the patients enrolled in MCOs, 9.3% reported a problem with their choice of physicians and clinics, compared with 7.8% of FFS patients ($P = .52$), and 6.6% of MCO patients reported a problem with their choice of specialists, compared with 4.9% of the FFS group ($P = .36$). Although not statistically significant, 2.7% of the MCO patients reported foregoing a treatment due to a problem with their health plan, compared with 1.1% of the FFS patients ($P = .07$). MCO and FFS enrollees were hospitalized within the previous 6 months at similar rates (65.5% of MCO patients vs 68.8% of FFS patients; $P = .44$). Of patients hospitalized in the previous 6 months, 18.9% of the MCO patients and 20.6% of the FFS patients spent time in the intensive care unit care ($P = .66$). Finally, MCO and FFS patients used hospice and home

care services at similar rates (31.7% and 33.5%, respectively; $P = .67$).

Care Needs and Economic Responsibilities

Of caregivers of patients enrolled in MCOs, 35.5% reported a substantial caregiving burden, compared with 33.0% of caregivers of FFS patients ($P = .59$). MCO patients were less likely to have unmet care needs for nursing care or homemaking than patients in FFS (3.5% MCO patients vs 8.4% FFS patients; $P = .05$). MCO enrollees were significantly more likely to report spending more than 10% of family income on medical expenses above and beyond insurance premiums (27.0% of MCO patients vs 17.6% of FFS patients; $P = .02$) (Figure 1). Yet there were no differences between MCO and FFS patients in their subjective sense of economic burden (58.8% vs 60.5%, respectively; $P = .70$) and likelihood of selling property or taking out a loan to pay for medical care expenses (10.1% of MCO patients vs 9.0% of FFS patients; $P = .62$).

End-of-Life Planning

Among the MCO patients, 49.9% had completed a written formal advance care directive, compared with 47.0% of the FFS patients ($P = .54$) (Figure 2). Of the MCO patients, 48.1% had filled out a healthcare proxy, compared with 46.7% of the FFS patients ($P = .76$). Similarly, patients enrolled in MCOs and FFS spoke with their caregivers about their end-of-life preferences at similar rates (72.0% of MCO enrollees vs 68.9% of FFS enrollees ($P = .47$) (Figure 2).

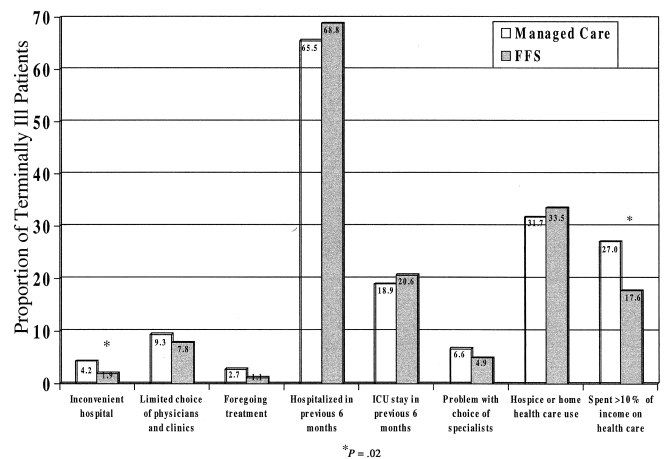


Figure 1. Proportion of terminally ill patients who reported on the following measures of access and use of healthcare services: 1) being required by insurer to use an inconvenient hospital ($P = .02$); 2) being limited by insurer in choice of physicians and clinics ($P = .52$); 3) having “postponed or gone without medical care or medicine” ($P = .06$); 4) having a hospitalization within previous 6 months ($P = .44$); 5) have been treated in the intensive care unit in the previous 6 months ($P = .66$); 6) being limited by insurer in choice of specialists ($P = .39$); 7) receiving hospice or home care services ($P = .67$); and 8) spending more than 10% of family income on medical expenses beyond insurance premiums ($P = .02$). All proportions reported are adjusted for differences associated with older age, religion, race, diagnosis of heart disease, severity of illness (i.e., being bed-ridden more than 50% of the day), and site of recruitment.

Care at the Time of Death

During the course of the study, 29.3% (289/988) of patients were documented to have died. Follow-up interviews were conducted with 256 of the caregivers (a response rate of 90.5%). Caregivers reported no differences in whether patients experienced a moderate or great amount of pain during the last 4 weeks of life (77.6% of MCO patients vs 67.1% of FFS patients; $P = .27$) (Figure 2). MCO patients were more likely than those in FFS to be bedridden 50% or more of the time during the last 4 weeks of life (82.2% of MCO patients vs 63.0% of FFS patients; $P = .03$). Of the MCO patients who died, 46.2% died at home, compared with 46.0% of FFS patients ($P = .98$).

Association Between Degree of MCO Penetration and Key Outcomes

Because there was a concern that associations between MCO penetration and outcomes might differ across study sites, the Breslow-Day test for homogeneity of odds ratios was performed for key outcomes. For example, there was no evidence of heterogeneity of the odds ratio for being bedridden ($P = .92$), pain ($P = .85$), or inconvenient location of hospitals ($P = .30$). Thus, the findings apply across all study sites.

DISCUSSION

This research presents the first comprehensive comparison of the personal experiences of terminally ill patients in managed care versus FFS settings. Overall, the outcomes measured were similar for patients enrolled in MCOs and those in FFS,

but enrollment in MCOs was positively associated with patients reporting the use of inconvenient hospitals, spending more than 10% of income on medical expenses, and poor functional status in the last 4 weeks of life.

This study reveals three specific findings. First, although the overall numbers are small, the managed care enrollees' outcomes with respect to access to care were comparable with the outcomes of their FFS counterparts on almost all measures. Although the overall rates were low, MCO patients were more likely to report using inconvenient hospitals and to spend more than 10% of their income on medical care beyond insurance premiums. These findings of difficulty with access to medical services among terminally ill patients in MCOs confirm long-standing concerns that have been reported for other MCO populations. Because of their compromised functional status and serious symptoms, being required to use an inconvenient hospital is probably more burdensome for the terminally ill than for patients who are less severely ill. However, many of the patients—especially those with Medicare—were able to choose their form of insurance and may have knowingly opted for health plans with lower initial premiums but greater restrictions and inconvenience. These restrictions on service may require higher out-of-pocket expenses when services are ultimately needed.

Second, despite vocal concerns about threats of MCOs to the integrity of the physician-patient relationship, few differences in the quality of the relationship between the MCO and FFS cohorts were found. Indeed, the overwhelming percentage of terminally ill MCO and FFS patients in this study reported extraordinarily high levels of trust in their physician. There were no differences in other aspects of the patient-physician relationship, such as physician advocacy for patients and good information transfer. Thus, when the physician-patient relationship means the most, at the end of life, patients in MCOs appear to be able to rely on their physician and are satisfied with their relationship.

Finally, terminally ill patients in MCOs did not report better experiences than those in FFS on any outcome measure. Despite the hope that MCOs could improve outcomes of serious illness through better case management, outcomes monitoring, and practice guidelines,^{19,21,22} there was no measurable effect in these six sites on amelioration of symptoms, lessening the burdens for the terminally ill, use of hospice and home care, or the rate of home deaths. One reason for this may be that the terminally ill are a relatively new segment of the managed care population. Consequently, MCOs may not have focussed their attention, energy, and resources on developing interventions to address the needs of dying patients. For example, in sites such as Tucson, St. Louis, and Worcester, where overall managed care penetration is comparatively high, penetration among terminally ill patients remains relatively low, 13.1%, 23.9%, and 16.6%, respectively. There was no evidence of heterogeneity among the high-penetration and low-penetration sites as far as the significant outcomes were concerned.

However, if end-of-life care is to be improved substantially, it is critical that MCOs recognize the unique needs of dying patients and use their knowledge, strengths, and resources to develop innovative strategies for improving care at the end of life.^{24,25,32} It is equally critical that risk-adjustment and structural incentives be developed so that

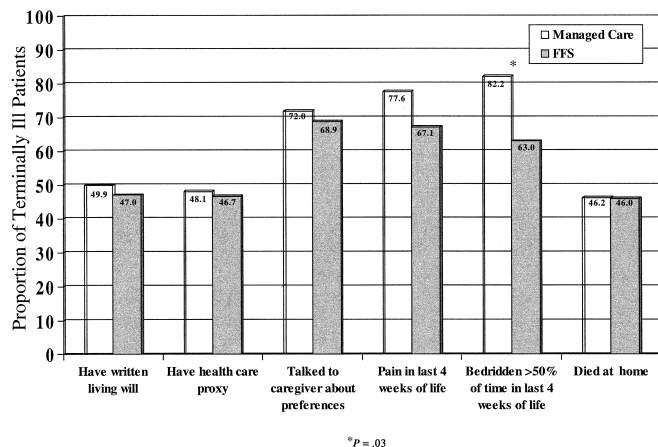


Figure 2. Proportion of terminally ill patients or their caregivers who reported: on the following measures of end-of-life care and preferences: (1) completion of written living will ($P = .54$); (2) completion of written proxy decision-maker form ($P = .76$); (3) experiencing a moderate or great amount of pain in the last 4 weeks of life ($P = .27$); (4) being bed-bound more than 50% of the day during the last 4 weeks of life ($P = .03$); and (5) dying at home ($P = .98$). All proportions reported are adjusted for differences associated with older age, religion, race, diagnosis of heart disease, severity of illness (i.e., being bed-ridden more than 50% of the day), and site of recruitment.

MCOs are not penalized when they strive to offer high-quality care to terminally ill patients.^{18,41}

This study has several main limitations. First, the study population may be unrepresentative. Because the patients' personal experience with care was sought mentally incompetent patients, such as those with Alzheimer's disease, were excluded. In addition, slightly more than half of the patients had cancer, whereas just less than one-quarter of mortality in the United States is due to cancer.⁴² This may reflect physicians' confidence in predicting a 6-month survival for cancer patients and the uncertainty in such predictions for patients with heart failure and other noncancer terminal illnesses.²⁵

Second, physicians who identified patients may have selectively referred patients with fewer symptoms and complaints, those living independently and with good social support, and those with whom they had good relationships. Because of the sensitivity of interviewing terminally ill patients, other studies of dying patients, including SUPPORT,³¹ have required the consent of patients' physicians before patient interviews. Thus, potential bias from physician referrals is inherent in research involving the terminally ill. Nevertheless, the sociodemographic profile of the study population reflects the one expected, based on the U.S. population and SUPPORT.^{28,29} Most importantly, physicians who referred patients did not know the hypotheses of this study and could not have anticipated that we would compare the experiences of MCO and FFS patients on the quality of the patient-physician relationship.

Third, a small proportion of patients could not be definitively assigned to the MCO or FFS groups and were included in the FFS group. Consequently, the number of MCO enrollees may have been undercounted.

Finally, patients were classified as belonging to MCOs without specifying the organizational structure, method of physician or hospital reimbursement, or whether the MCO had special programs for terminally ill patients. Thus the managed care population includes enrollees in staff-model and looser independent provider association-type MCOs. These characteristics of organizational structure may be more determinative of the outcomes assessed than mere MCO enrollment. Additional studies are needed to define whether different models of MCO structure and various modes of reimbursement affect the experience of terminally ill patients.

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