The Public Policy Institute, formed in 1985, is part of the Research Group of the AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This paper represents part of that effort.

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FOREWORD

As the population ages and technological advancements proliferate, the public is paying more attention to the nature and costs of dying in America. Indeed, care at the end-of-life has emerged as an important health care issue. There is growing research to show that location and circumstances under which death occurs vary widely throughout the nation.

Many factors play a role in what type of care one gets at the end-of-life—community norms, the culture of medical practice, and geographic location, to name a few. The shift to managed care in the private sector and, increasingly so, in both Medicaid and Medicare, raises the question of whether capitated delivery systems approach end-of-life care differently from the fee-for-service system.

An often cited benefit of managed care is its ability to organize and coordinate a range of services across a continuum of care sites; in contrast, fee-for-service care is described as more fragmented and episodic. Consumers and providers alike would agree that continuity would enhance care for terminally ill enrollees who may move from one care setting to another as they approach death. Do managed care plans maximize the unique features that potentially allow them to be more responsive to patient needs? Or do these same features create barriers to good end-of-life care because of the inherent disincentive in managed care to provide necessary services?

As is evident from the literature review that is part of this report, very little is known about how managed care plans actually provide end-of-life care. It is probably reasonable to assume that just as there is tremendous variation among managed care plans in the delivery of primary and acute care for episodic illness, there is likely wide variation in how they provide care at the end of life as well.

The Public Policy Institute commissioned Peter Fox to identify and interview senior managed care medical managers about end-of-life care in health plans. We hoped that through informal interviews with such experts, we could develop a context to then frame research questions and formulate a research agenda on end-of-life care in managed care. As Dr. Fox notes in his paper, it is not possible to generalize from his findings; the number of individuals interviewed was small and not representative of the universe of managed care plans or administrators. Although his discussions with these experts were wide ranging, the issues touched on must be addressed at greater length. Nevertheless, Dr. Fox was able to have a candid exchange and explore the relevant issues with experts who have given end-of-life care thought and attention. In spite of the report’s limitations, we hope that the insights shared about how selected plans address end-of-life issues will begin to shed light on this subject and help form the basis for further discussion and study among policy analysts and decision makers.

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EXECUTIVE SUMMARY

Background

Over 6 million Medicare beneficiaries are enrolled in health maintenance organizations (HMOs), which are required to provide all Medicare-covered benefits in return for a fixed monthly fee, an arrangement referred to as “capitation.” Some of these HMOs, in turn, contract with provider groups and pay them on a capitation basis. HMOs and capitated provider groups are collectively referred to herein as managed care organizations (MCOs). Although MCOs are recognized as having the potential to coordinate a comprehensive set of benefits across the continuum of care, little is known about how they provide end-of-life care.

Purpose

The purpose of this paper, which is exploratory in nature, is to shed light on how certain MCOs provide care to their Medicare enrollees at the end-of-life and to determine the extent to which the delivery of end-of-life care in managed care has been explored in the research literature.

Methodology

The author interviewed 19 individuals in senior level medical management positions in the managed care industry. Interviewees were queried about how their respective organizations provide end-of-life care. In addition, a literature review of end-of-life care in managed care settings was conducted.

To determine how MCOs have addressed end-of-life care, the author inquired about their use of advance directives (e.g., how these were promoted, the proportion of enrollees with advance directives, and physician awareness of policies on advance directives); their hospice relationships (e.g., formal or informal relationships, and programs for enrollees who do not qualify for Medicare hospice benefit); and whether other end-of-life care initiatives had been implemented.

Principal Findings

The empirical research on end-of-life care is scant, although it has expanded in recent years; there is even less literature that is specific to the managed care setting. In general, the findings in the extant literature are inconclusive.

End-of-life care in MCOs is heavily influenced by a broader societal context, making it difficult to isolate factors or activities that relate specifically to managed care. The issue is further complicated by such factors as how participating physicians are organized to practice medicine and the relationship between the respective roles of the health plan and medical group or delivery system.
Most of the interviewees reported that their respective organizations simply inform new enrollees through printed materials about advance directives. The interviewees expressed skepticism about the value of advance directives, citing several reasons for this attitude. However, some of the MCOs periodically remind their members about the desirability of having an advance directive; others attempt to enhance member awareness of the need for an advance directive by including a question on this subject in the course of periodic health assessments. Some plans check for a provider’s notation in the chart that the subject of advance directives has been addressed with patients.

Health plans differ in how they relate to hospices. A few own their own hospices, although Medicare beneficiaries eligible for this benefit may choose any hospice in the community. Since Medicare reimburses hospices directly, even for beneficiaries enrolled in managed care plans, MCOs are not required to have organized hospice arrangements.

Interviewees were asked about their views of hospice, whether it was financially advantageous to refer enrollees to hospice care, and whether they favored the current Medicare “carve out” of the hospice benefit. Most interviewees stated that physician referrals to hospices were too infrequent and, often, late (i.e., a few days before death), which is also true in the fee-for-service system. To address this concern, several MCOs have mounted physician education programs.

Interviewees were also asked if their organizations had implemented any special end-of-life care initiatives. Several interviewees reported that their organizations either had developed or were developing palliative care teams as well as other initiatives to address end-of-life care. Several examples are provided.

Many managed care organizations have paid little or no attention to end-of-life care beyond meeting federal requirements. Numerous barriers to better end-of-life care in MCOs were identified, the most significant of which were environmental factors, such as physician attitudes, and the organization of medical practice generally, whether fee-for-service or managed care. Other barriers such as concern with community image and the lack of either an accreditation standard or HEDIS measure on end-of-life care were also cited.

Conclusions

It appears that a growing number of MCOs may have either initiated or intend to initiate programs on end-of-life care. Several of the initiatives that have been mounted may serve as useful prototypes. In addition, there may be a natural progression associated with the implementation of care management programs. As MCOs implement more extensive care management programs for chronically ill and disabled beneficiaries, the attention paid to end-of-life care is likely to increase.
INTRODUCTION

More than 72 million Americans, including some 6 million Medicare beneficiaries, are enrolled in HMOs, organizations that receive capitation payments in return for agreeing to provide a comprehensive range of benefits to their enrollees.\(^1\) Some of these HMOs, in turn, capitate provider groups with which they contract. These provider groups include hospitals, which may share risk with their admitting physicians; true (“single taxpayer ID”) group practices; and associations of physicians in independent practice. Collectively, HMOs and capitated provider groups are referred to herein as managed care organizations (MCOs). However, this paper refers to HMOs or health plans where the observation is applicable to them but not to risk-bearing provider organizations. The focus of this paper is on organizations that are capitated or bear considerable risk rather than, for example, the typical preferred provider organization (PPO), which achieves savings through provider discount or limited utilization management such as prior authorization of inpatient stays.

MCOs offer the promise of organizing the healthcare delivery system in a manner that enhances coordination of care, including care for individuals who are dying. Poor end-of-life care can result in needless suffering for both dying patients and their loved ones. This paper is based primarily on interviews with physicians and others in senior medical management positions within MCOs (see Appendix A for list of interviewees). It is exploratory in nature. The number of interviewees is small when one considers the diversity in the organizations they represent, as reflected in differences in HMO model types and provider organizations. Also, interviewees were not randomly selected. Rather, they are known, or were referred to, the author and are individuals who he believes to be particularly thoughtful on medical management issues.

Nationally, care at the end of life is receiving increasing attention, and more extensive efforts are underway than are reflected in this paper. These efforts may encompass managed care but are generally broader in their scope. The Robert Wood Johnson Foundation has made the topic a priority, as reflected in its “Last Acts” program. Greater research and educational activity is occurring as illustrated by the creation of the Center to Improve Care for the Dying at George Washington University (Joanne Lynn, Director) and the National Task Force on End-of-Life Care in Managed Care, convened by the Center for Applied Ethics and Professional Practice at the Educational Development Center, Inc., in Newton, MA (Mildred Z. Solomon, Principal Investigator).

The next section of this paper summarizes the literature on end-of-life care in the managed care setting. After that, we review some of the confounding and external factors that influence the behavior of MCOs with respect to end-of-life care. The subsequent section describes initiatives of MCOs with regard to advance directives, hospice relationships, and other activities

that relate to end-of-life care. Then, the barriers to better end-of-life care in MCOs are discussed, followed by some concluding comments.

LITERATURE REVIEW

The empirical research on end-of-life care is scant, although it has expanded in recent years; there is even less literature that is specific to the managed care setting. In a study of frail, older adults, Experton et al. found no differences between expenditures for service utilization by HMO and fee-for-service enrollees. However, the data were limited to patients receiving services from Sharp Home HealthCare, a home health agency in San Diego, CA, limiting the extent to which one can generalize from the results.\(^2\) Another study, by Virnig et al. scheduled for publication in early 1999, compares the use of hospice among Medicare beneficiaries who are enrolled in HMOs with those who remain in fee-for-service (“nonenrollees”) using Medicare files for 1992 for four counties in South Florida.\(^3\) The findings included the following:

- Some 26 percent of HMO enrollees died in hospice, compared to 18 percent of nonenrollees, indicating that enrollees made greater use of the hospice benefit.
- The proportion of patients with a diagnosis of cancer was virtually identical – 59.2 percent for HMO enrollees vs. 60.7 percent for nonenrollees\(^4\)
- For cancer patients, the median length-of-stay in hospice was 20 days for HMO enrollees compared to 14 days for nonenrollees.
- HMO enrollees were more likely than nonenrollees to survive in hospice for more than 180 days, also indicating longer lengths of stay.

The data that Virnig et al. analyzed suffer from two limitations. First, they are somewhat old, i.e., for 1992. Second, they refer exclusively to beneficiaries living in south Florida (Miami and nearby counties), where both HMO behavior and the acceptance of hospice may not be representative of the US.

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A recent publication of the Institute of Medicine (IOM) provides a comprehensive overview of the literature on care at the end of life. However, the portions on managed care address its advantages and disadvantages mostly in theoretical terms. On the positive side, the publication cites, for example, the potential for improved coordination and continuity of care. On the negative side, the supposed inexperience (refuted by other literature) of health plans in enrolling persons with chronic illness is mentioned, as is the concern with whether the financial incentives embodied in capitation results in under-service. The publication also reports that some hospices criticize HMOs serving non-Medicare populations for micro-managing the hospice benefit.

Like the IOM report, Miles, Weber, and Koepp address end-of-life care in MCOs from a theoretical perspective. Features of MCOs that are conducive to good end-of-life care include their ability to integrate care across providers and treatment sites, their potential to ensure that advance directives follow the patient who is transferred among treatment sites such as into the hospital or emergency room, the decrease in the “perverse incentives against timely hospice referrals,” and the decrease in “the preoccupation with certifying that patients have less than six months to live before being referred to hospice that now causes hospice care to be delayed until just before death.” The negative factors include MCOs’ not having the same beneficent obligation to individual patients as do physicians and the potential for clinicians, who face financial incentives, to assume a diminished patient advocate role, particularly as prolonged palliative care can be expensive.

In a similar vein, Morrison and Meier comment that little is known about the impact of managed care on end-of-life care. They hypothesize that care of the terminally ill could significantly improve under managed care, arguing that the financial incentives could reduce the number of needless tests and procedures that are commonly inflicted on dying patients. The ready access to primary care physicians (PCPs) and the potential for practice guidelines to educate physicians about palliative medicine also are mentioned as favorable characteristics. However, the authors are uncertain whether the potential will be realized because of uncertainty surrounding the impact of the incentives embodied in capitation.


6 For example, Lyle Nelson et al., “Access to Care in Medicare HMOs, 1996,” Health Affairs, Vol. 16, No. 2 (March/April 1997), pp. 148-156, report that HMOs with Medicare contracts have significant numbers of disabled. Also, Teresa Fama, Peter D. Fox, and Leigh Ann White, “Do HMOs Care for the Chronically Ill?,” Health Affairs, Vol. 14, No. 1 (Spring 1995), pp. 234-243, conclude that among persons under age 65, the prevalence of chronic illness among HMO and indemnity plan enrollees is similar.


Beyond the issue of managed care, there is some empirical literature on advance directives and hospice care. It, too, is inconclusive, although generally positive. In a meta-analysis of the relevant literature, Emanuel finds that studies on the cost savings associated with advance directives and hospice care are not definitive, in part because of methodological questions that characterize individual research efforts. Nonetheless, he concludes that the two together can achieve savings in medical costs of 25 to 40 percent during the last month of life.

The “Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT),” a multi-site study that did not specifically study managed care, found that patient end-of-life preferences were often disregarded and that patients who wanted to die at home commonly died in the hospital after receiving more aggressive treatment than that for which they had expressed a preference. The study also found that the geographic variation in the proportion of patients who died at home rather than in the hospital was not explainable by differences in sociodemographic or clinical factors or patient characteristics; rather the variation appears related principally to differences in the characteristics of local health systems.

In a review of the hospice experience, Rhymes concludes that “although [the] hospice philosophy is appealing, evidence to support its purported advantages over conventional care is mixed.” She cites as an example the National Hospice Study, which followed 1,754 terminal cancer patients in 14 conventional care settings and 40 hospices, 20 of which were home-based and the other 20 hospital-based. The study found quality of life to be similar. Pain and symptom control were found to be somewhat better in inpatient hospices than in conventional care or home care hospices. Quality of death during the last three days of life was found to be significantly better for hospice patients than for patients receiving conventional care. Overall patient and caregiver satisfaction was comparable or better in hospice than conventional care. Caregiver burden was slightly higher in hospice. The empirical analysis was conducted during the 1980s, and the findings might be different today.

Finally, Cher and Lenert, using Medicare administrative data on admissions to intensive care units in California hospitals for FY 1994, compared HMOs and fee-for-service patients in terms of whether their lives were prolonged by services that were judged to be of no value.

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ultimately. They found the likelihood that patients would receive “potentially ineffective care” was less among HMO patients. Also, HMO patients were not more likely to die in the hospital rather than in other settings and only slightly more likely to experience death within 100 days of discharge. The authors conclude that “HMO practices may be better at limiting or avoiding injudicious use of critical care near the end of life.”

**CONFOUNDING AND EXTERNAL FACTORS**

End-of-life care in MCOs is heavily influenced by a broader societal context, making it difficult to isolate factors or activities that relate specifically to managed care. Indeed, interviewees consistently cited this broader context, reflecting, notably, patient and physician attitudes rather than internal plan constraints, as representing the greatest barrier to improved end-of-life care.

Patients and their families vary in their willingness to address end-of-life issues, with many being reluctant to do so. Death is a matter that many Americans prefer not to contemplate. This unwillingness to confront the inevitable is at times reflected in the perspective that technology can solve all problems, or at least has a chance of doing so, leading to an attitude of never wanting to “give up.”

Societal attitudes as well as medical training influence physician behavior. Physicians may share the same reluctance as others to confront the matter for themselves. Even if they are able to do so, they may be uncomfortable discussing the topic with their patients. In addition, helping someone die comfortably commonly entails relating to family members and, often, to community social services agencies, for which many physicians lack the training or orientation. Also, medical training focuses on diagnosis and cure, not helping someone to die, which can be taken as an admission of failure or defeat. Finally, many physicians are ill-trained in pain management and, also, have only a weak understanding of what hospices do or of the hospice benefit.

The manner in which physician practices are organized, whether in fee-for-service or managed care, is another confounding factor. Office practice typically entails seeing patients at least every 15 minutes. End-of-life planning requires a joint effort with the patient and family members and does not fit well into the standard time slots allocated for office visits. Hospitalizing the patient can be easier for the physician than making the effort to deal openly and comprehensively with end-of-life issues. On the other hand, in both managed care and fee-for-service, the organization of medical practice creates an incentive to refer to hospice in order to

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14Field and Cassel (p. 216) report that only 6 out of 126 medical schools had separate required courses on care at the end of life, although 120 addressed the topic as part of a broader course.
divest oneself of a time-consuming patient, albeit perhaps only after available technologies have failed and within a matter of days of death.

Another complicating factor in understanding the impact of managed care on care at the end of life is the differing perspectives on the appropriate role of the health plan vs. that of the delivery system. In staff and group model plans, the insurance and delivery system functions are intertwined, and the plans commonly do work with physicians and other providers to address end-of-life care. On the other hand, in Independent Practice Association (IPA) plans, i.e., health plans that contract with physicians who serve multiple payers, the health plan relationship with its physicians is generally more distant. Broadly speaking, in these plans the nature of the contracts with physicians is of two types. The first is where the health plan contracts directly with individual physicians or true (single taxpayer ID) group practices. The second is where the health plan contracts with physicians or physician groups through an intermediary entity such as a physician-hospital organization (PHO) or an association of physicians in independent practices, i.e., IPAs. In either case, much of the risk may devolve from the health plan to the providers. It is particularly where the medical groups accept much of the risk that they resist being told how to organize their medical practice, including the delivery of end-of-life care. As a result, attributing levels of activity or responsibility to the MCO vs. the delivery system can be difficult.

Finally, public attitudes vary by community and influence the saliency of end-of-life care within MCOs and their willingness to address it. Where community-wide efforts have been undertaken on advance directives and end-of-life care, the fear of MCOs that their efforts could be misinterpreted as reflecting the desire to promote death to save money is lessened. In Oregon, physician-assisted suicide has been a prominent political issue, culminating in its being legalized under limited circumstances in 1994 through a ballot referendum. Reflecting the strength of the opposition to physician-assisted suicide, in 1997 the legislature placed on the ballot a proposal to repeal the 1994 law. The repeal effort was defeated by a slim margin. In that state, at least one large plan with a Medicare contract feared being embroiled in political controversy and resolved to refrain from addressing end-of-life care as much as possible; in this case the plan simply complied with federal requirements, relating principally to informing enrollees about advance directives. This minimizing of end-of-life issues included instructing case managers to be responsive to patients and families but to avoid being proactive in raising hospice as an option.

INITIATIVES IN MCOs

Many MCOs have paid little or no attention to end-of-life care. Among HMOs, group/staff models were found to exhibit greater attention to end-of-life care than IPAs. This section presents initiatives that were identified during the course of the interviews. To reiterate, the sample of MCOs contacted is neither comprehensive nor representative. In addition, the attribution of an initiative to a particular organization does not imply that other plans have not mounted similar efforts.
Advance Directives

Most health plans simply inform new enrollees through printed materials about advance directives, as required under the Patient Self-Determination Act (PL 101-508), enacted in 1990. The reasons for not being more proactive include having higher priorities, believing that primary responsibility should rest with the delivery system rather than the health plan, and being skeptical of the value of doing so. This skepticism stems from the view that advance directives are often not available when needed, their largely being ignored when they are available, and their often not being sufficiently detailed to provide guidance at the appropriate time. Furthermore, several respondents said that many patients change their minds regarding their desires for treatment as they approach death.\(^\text{15}\)

Some health plans periodically communicate to their membership the desirability of advance directives. Keystone-East, an IPA-type HMO that is a wholly owned subsidiary of Independence Blue Cross in Philadelphia, annually provides printed information on advance directives to its membership, including the desirability of updating them. Enrollees are also encouraged to discuss end-of-life issues with families, physicians, and, if appropriate, attorneys. The Sutter Health System, a delivery system in California that is capitated by several health plans, has assembled a packet of information on advance directives for physicians to distribute in their offices.

Several health plans (e.g., Health Plan of Nevada, a mixed model HMO under Sierra Health Services, and many Kaiser regions) perform annual health assessments on Medicare members that include a written questionnaire completed by the member. One question involves advance directives; the inclusion of this question enhances enrollees’ awareness of advance directives and lets physicians know whether or not the patient has completed one. Among Kaiser enrollees in California, 60 percent of frail older persons and 30 percent of nonfrail older persons were found to have advance directives.

Group Health Cooperative of Puget Sound, a staff model HMO (now part of the Kaiser Permanente system) in the State of Washington, has introduced the concept of “advanced planning” as part of the annual physicals and health assessments that it offers Medicare enrollees. For patients judged to be at risk of deterioration, advance directives are addressed as part of a broader set of topics, designed, for example, to encourage planning ahead in anticipation of an individual’s possible future need for long-term care. Health plan staff believe that this broader context reduces some of the stress associated with talking about advance directives.

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\(^{15}\)There is research evidence that choices are generally stable over time. See Linda L. Emanuel et al., “Advance Directives: Stability of Patients’ Treatment Choices,” Archives of Internal Medicine, Vol. 154, No. 2 (January 24, 1994), pp. 209-217. However, there is apparently no research specifically on whether patients change their mind once they have accepted that they are terminally ill.
Many IPA-model health plans perform periodic visits to primary care physician (PCP) offices as part of recredentialing reviews, which include reading a sample of medical charts. The scores from these reviews affect PCP remuneration. Aetna/US HealthCare has adopted a standard that the medical chart should include an advance directive, and Keystone East, as part of its periodic evaluation of PCP practices, looks for a notation that the PCP has discussed the topic with patients.

Advance directives may not be available when needed. To address this problem, the group division of Harvard Pilgrim Health Care, a health plan with both a group and an IPA division, is mounting an initiative to place advance directives in both physicians’ offices and in the computer system of the two major hospitals with which the plan contracts. This is intended to ensure that patients’ advance directives are available when needed, such as when an enrollee uses the emergency room. Group Health Cooperative in the Seattle area has a central registry for advance directives that can be accessed by hospitals, including their emergency rooms; one limitation is that the registry is not automated.

**Hospice Relationships**

For Medicare HMO enrollees, the hospice benefit is “carved out,” i.e., the hospice organization is paid directly by the Medicare program rather than by the HMO. The member remains part of the HMO for nonhospice services only, for which the plan is paid a reduced rate.\(^1\)

Health plans differ in how they relate to hospices. A few HMOs own hospices, which may also serve nonmembers. Regardless of the relationship, the Medicare enrollee is free to choose any hospice in the community, and many health plans do not have contracts with hospices; such contracts are relevant only for non-Medicare members, since the Health Care Financing Administration (HCFA) pays for hospice care directly. Where there are contracts, the focus for Medicare patients is not on reimbursement but on access and quality, e.g., services being readily available 24 hours a day, quick response time to member telephone calls.

MCOs vary in the extent to which patients who do not have cancer are referred to hospice. This variation may be more reflective of community than MCO practices. Diagnoses besides cancer for which hospice is used include advanced congestive heart failure, chronic

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\(^1\)The HMO receives three streams of payment for enrollees in hospice. First, for non-hospice services, it bills the Medicare fiscal intermediary fee-for-service for the Medicare-reimbursed portion of services. Second, it receives a capitation amount from HCFA equal to the portion of Medicare capitation benefits for non-hospice enrollees that is used to finance additional services beyond the standard Medicare benefit package. Third, if the HMO charges premiums to enrollees, it can continue to do so. (See Code of Federal Regulations, Vol. 42, Subpart F, Part 422.266.) Some health plans find this billing arrangement cumbersome and report having difficulty obtaining the moneys due them.
obstructive pulmonary disease (COPD), and neurological diseases such as Parkinson’s, Amyotrophic Lateral Sclerosis (ALS), and Alzheimer’s. Many interviewees regard hospices as generally oriented towards meeting the needs of cancer patients rather than those of patients with other conditions.

The Medicare hospice benefit is, by law, limited to patients whose prognosis for living is less than six months. The Office of the Inspector General (OIG) in the U.S. Department of Health and Human Services, as part of its “Operation Restore Trust,” has criticized some hospices for admitting too many patients who lived longer than six months.\textsuperscript{18} Unfortunately, prognoses for individual patients are often uncertain, and a number of interviewees volunteered that the OIG’s efforts have led to HMOs’ being more conservative in promoting use of hospice, especially for noncancer patients.

The general perception among the MCOs interviewed is that physician referrals to hospice are too infrequent and often late, i.e., a few days before death. To address this concern, some MCOs have mounted educational efforts to inform physicians about hospice. However, rarely have MCO’s developed formal guidelines. Also, in the last few years, many MCOs have created task forces to address end-of-life issues, with a particular focus on hospice.

Interviewees were asked about the strengths and weaknesses of hospice. Positive characteristics mentioned included: the caring attitude of hospice workers; the ability of hospices to work with family members, including integrating them into decision-making and teaching caregiving skills; 24-hour availability; the ability of hospices to provide supportive services including, in some cases, respite care; and their ability to control pain well. As noted earlier, one negative is that some hospices are viewed as being more inclined to accept cancer patients than those with other conditions. Other criticisms of hospice included: poor communication with health plan administrators, physicians, or case managers (“silo mentality”), resulting in a lack of coordination between the rendering of hospice and non-hospice services; inflexibility in the use of durable medical equipment vendors; and inappropriate discussion with family members and patients about payment or coverage, matters rightly concerning hospice and the HMO. One interviewee, a geriatrician, felt that some hospices in her area were better than others in providing what families perceived as a tangible service; some families were reported to be frustrated at receiving little benefit from the hospice referral.

Interviewees were asked about whether transferring a dying patient on Medicare to hospice was financially advantageous or whether the HMO was financially better off incurring the costs for these enrollees and retaining the premium income. Responses ranged widely. Only two respondents reported having data on the subject, and the data led to opposite conclusions. About two-thirds of interviewees said that they had not thought about the matter or suggested it might

be a wash.\textsuperscript{19} Those who had an opinion split evenly between those who thought transferring patients was likely to be financially advantageous and those who regarded it as disadvantageous.

Patients incur considerable costs towards the end of life.\textsuperscript{20} However, interviewees who questioned whether transferring a member to hospice was advantageous argued that generally, once the patient was ready for hospice care, the expensive interventions had already been undertaken. They also observed that there are administrative costs associated with the transfer and with continued involvement with the patient, including the cost of keeping the patient in the MCO’s case management program. Finally, some respondents commented that, even though, technically, Medicare pays for nonhospice services on a fee-for-service basis, many MCOs were not set up to bill fee-for-service. (See note 18.)

Most interviewees favored ending the carve out. A few had no opinion, and two said that it would make little difference, in one case because relationships with hospice were good (the MCO owned a hospice), and in the other because hospice was rarely used. The major reason for wanting to eliminate the carve out was to enhance coordination of care. For example, hospice enrollees select a PCP for purposes of providing hospice services; if the hospice PCP is not a participant in the health plan, enrollees may find themselves under the medical supervision of two PCPs. Further, the HMO enrollees in hospice may also have two sets of case managers. In addition, the current structure was viewed as generating conflict and gaming over which organization should pay for particular services. For example, where the HMO covers prescription drugs, questions can arise regarding which party—the HMO or the hospice—is liable.

Neither hospice nor consumer representatives were interviewed in preparing this paper. However, most of the hospice leadership fear that elimination of the carve out will negatively affect the organization’s finances. In addition, some consumers are likely to be concerned that eliminating the carve out would reduce their choice of hospice because, presumably, access would be limited to hospices that were part of the health plan’s network, as is true for other services.

Some interviewees felt that eliminating the carve out would require a change in health plan orientation. Hospices provide certain services that traditionally HMOs have not covered, such as homemaking services and respite care, spiritual and psychological counseling for patients and their families, and bereavement counseling for family members after death has occurred. Hospices also serve both enrollees and family members, whereas HMOs are contracted to serve enrollees only. Volunteers are recognized in the Medicare Act as an integral part of serving dying patients. In addition, many Medicare HMO enrollees do not have a drug benefit or they may have a limited

\textsuperscript{19}At first blush, at least, this finding is surprising. However, many of the interviewees do not deal regularly with public policy issues. Also, some may be reluctant to consider, or perhaps admit to themselves, that health plan profitability would enter into their thinking about the delivery of care for dying patients.

benefit, whereas patients in hospice have unlimited coverage of palliative and other drugs that are part of the hospice plan of care.

If the carve out were discontinued, the method of payment to HMOs would need to be determined. Options include the following:

1. Blend existing hospice payments into the amounts that Medicare pays health plans. The additional payment would be small, given the low number of beneficiaries who both die and access hospice services in any given year.\(^{21}\)

2. Create a separate “rate cell” and payment amount for beneficiaries who enter hospice.

Assuming that the payment rate for enrollees in hospice is higher than that of other cells, the second option creates the presumption of a financial incentive to encourage enrollees to join hospice, raising the issue of whether this incentive is the desired one; the incentive in the first option is less clear.\(^{22}\)

**Other End-of-Life Initiatives**

A number of MCOs have developed, or are developing, various palliative care teams, which can include physicians, nurses, case managers, and social workers. The functions of the teams can range from consulting with the patient’s physician by telephone to assuming responsibility for direct care. Members of the team also help patients and their families accept that the end of life is approaching in order to enhance the quality of life and the personal interrelationships for the time remaining.

Kaiser, in parts of California, initiated a hospice-type program for patients who were in the hospital or skilled nursing facility, were within a couple of days of death, did not want to go home to die, and did not want aggressive treatment. These patients have been allowed to remain in the hospital or nursing home, and palliative services, but not active treatment, were provided. From a cost perspective, the program has been found to be budget-neutral.

The Sutter Health System both owns physician practices and has formed an IPA for community physicians. Physicians who work for the group practice that is part of the Sutter

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\(^{21}\) In 1995, out of 37,152,000 Medicare beneficiaries eligible for Part A benefits, 309,336 beneficiaries (0.8 percent) used the hospice benefit. Derived from *Health Care Financing Review: Medicare and Medicaid Statistical Supplement, 1997* (Health Care Financing Administration, Baltimore, M.D.), pp. 23 and 142.

\(^{22}\) With the introduction of the risk adjustors recently announced by HCFA, the incentives are unclear under both options. See *Changes in Methodology since 1999 Rates: Risk Adjustment (Medicare+Choice Rates -- 45 Day Notice*, available on the Internet at www.hcfa.gov.
system have convened a physician-led task force that evolved out of “Extreme Care, Humane Options (ECHO),” a community-wide effort in the Sacramento, CA, area to better understand public preferences with respect to end-of-life care.23 For example, one problem that Sutter is addressing is the lack of clarity among physicians regarding what constitutes appropriate comfort care. Another problem is the lack of coordination that results from multiple physicians participating in the care of patients, particularly in the intensive care unit (ICU) or across care settings such as the ICU, the regular ward, the skilled nursing facility, and the home. The task force has a separate effort on neonatal and child end-of-life issues.

Also, physicians in the Sutter IPA have established their own programs that include attending community-based train-the-trainer sessions. Physician trainers attend a day-and-a-half session, which consists of both formal instruction (e.g., on ethics, palliative care management, legal considerations, and assessment of patient capacity for decision-making) and role playing.

Other initiatives in MCOs include the following:

- The medical group associated with the Henry Ford Health System is developing a CD-ROM for patients on end-of-life issues. Through an interactive process, patients can complete advance directives, which can be entered directly into their electronic medical records.

- Several MCOs have programs to train case managers on end-of-life care.

- Keystone-East conducts training programs on the basics of managed care, including a module on end-of-life care, for the skilled nursing facilities with which it contracts.

- Group Health Cooperative of Puget Sound is developing a set of practice guidelines, referred to as “senior roadmaps,” for care of elderly persons; these guidelines will address end-of-life care.

- Aetna/US HealthCare has monthly teleconferences with its key Medicare staff from its plans around the country that regularly address appropriate use of hospice care. Participants in these calls, typically numbering between 40 and 60 people, include medical directors, nurses and case managers in leadership positions, utilization management staff, and compliance personnel.

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23 ECHO adopted five principles, which the Sutter System is following: (1) patient autonomy; (2) avoiding harm; (3) benefiting the patient; (4) medical integrity and the goals of medicine, defined as the maintenance of well-being and functioning that constitutes a quality of life that is satisfactory to the patient; and (5) wise use of societal and personal resources. See Extreme Care, Humane Options, Community Recommendations for Appropriate, Humane Medical Care for Dying or Irreversibly Ill Patients (Sacramento Healthcare Decisions, January 1997).
Finally, within the past year a significant number of MCOs have convened task forces on end-of-life care.

**BARRIERS TO BETTER END-OF-LIFE CARE IN MCOs**

Respondents universally felt that the most significant barriers to better end-of-life care derived from the broader context in which MCOs operate, such as patient and physician attitudes, and the manner in which medical practice is organized, whether in the fee-for-service system or under capitation. Many MCOs have not addressed end-of-life issues, either because such issues have not been on their radar screens or because end-of-life care is regarded as a low priority compared with, for example, the development of effective case management, disease management, and other secondary and tertiary prevention efforts for enrollees who are not terminally ill.

The remainder of this section discusses MCO-specific barriers that were cited during the interviews.

**Community Image**

Interviewees were asked about the role of community image in discouraging attention to end-of-life issues, i.e., whether there was concern that addressing end-of-life care could generate a public reaction that the MCO was trying to terminate the lives of expensive patients. Certainly, no MCO markets the idea that it offers superior end-of-life care.

Some respondents felt that end-of-life care was an issue that should be avoided in light of the attacks directed at managed care in the media and by elected officials. However, most interviewees regarded community image as only a consideration that should result in caution and sensitivity rather than avoidance. A number of respondents felt that the greater willingness among the public to discuss end-of-life issues in recent years had decreased the potential for negative reaction directed at MCOs. A minority felt that community image was simply not a problem, although it might have been some years ago.

**Absence of NCQA or HEDIS Focus**

End-of-life care is not addressed in either the accreditation reviews that the National Committee for Quality Assurance (NCQA) performs of MCOs or the Health Plan Employer Data and Information Set (HEDIS) performance measures. One HEDIS measure\(^\text{24}\) addresses functional decline, with death being assigned the minimum score, potentially creating the incentive to keep

\(^{24}\) Medicare Health Outcomes Survey (HOS)
patients alive inappropriately. Indeed, a focus on functional status for the dying patient runs the risk of being misplaced.

The majority of interviewees felt that end-of-life care should be addressed by NCQA and/or HEDIS in order to increase attention levels, since MCOs tend to devote resources to what is measured under both HEDIS and the accreditation process, at times to the neglect of other services. Interviewees regarded good end-of-life care as having as much to do with quality of care as does, for example, the performance of mammograms.

Some respondents suggested that evidence in medical charts that the physician has discussed end-of-life care with patients over age 65 would be a reasonable measure. Another suggestion was that accreditation standards require MCOs to demonstrate that they have paid attention to end-of-life issues for high risk groups. Finally, the availability of a pain management program might be an accreditation standard.

On the other hand, a few interviewees were ambivalent, in part because of uncertainty surrounding the identification of meaningful measures in light of the difficulty in quantifying good end-of-life care. One interviewee argued that measuring the presence of advance directives has limited value absent some assurance that they are used. Another interviewee commented that even the academic community has been unable to define good end-of-life care.25

Other Barriers

Other barriers cited included the following:

- The hospice carve out, discussed above.
- Provider resistance to plan direction on patient care management, including care at the end-of-life, when the provider group is capitated by the plan.
- The lack of the availability of advance directives to providers in a timely manner (e.g., in the emergency room) or their not being sufficiently explicit; the absence of processes to encourage enrollees to keep their advance directives current.
- The inability to predict when death will occur, which has reduced the willingness to refer to hospice. This concern has been heightened by efforts of the Office of the Inspector General and HCFA to combat admission of patients who might live beyond the statutory six-month limit.

25 It should be noted that some academicians and researchers would disagree with this assertion. See, for example, the report of the Committee on Care at the End of Life, Institute of Medicine, “Approaching Death, Improving Care at the End of Life”. National Academy Press. Washington, DC, 1997.
CONCLUSION

This paper shows that a number of MCOs have launched or are planning initiatives related to end-of-life care. On the other hand, many MCOs, particularly health plans as opposed to capitated provider groups, have done little to address the issue. Although death can occur at any age, most dying patients are on Medicare. Health plans with Medicare contracts vary enormously in the extent to which they have addressed the unique medical, functional, and social needs of older persons, e.g., by designing and implementing dedicated health promotion and case management programs.

Contributing to MCOs’ lack of attention is the concern with community image and the improbability that a health plan would market its end-of-life care for fear of arousing a cynical public response concerning the plan’s motivation for providing good care in this area. The community image issue is less prominent where there have been community-wide efforts to address end-of-life care, creating an environment where open discussion is encouraged, as has happened, for example, in Sacramento, CA.

In recent years, MCOs have paid greater attention to disease management, particularly for conditions such as diabetes, coronary artery disease, and pulmonary disease. Disease management is premised on the desirability of maintaining health, retarding deterioration, and maximizing the patient’s level of functioning through instruction in self-care and active early intervention. Care for the dying patient entails a very different philosophy. Depending on personal preferences, optimal care may entail accepting that death is approaching, calling for a different set of care processes that focus on pain relief rather than recovery, and on the avoidance of the artificial prolongation of life. The intersection of disease management, as it is commonly implemented, and good end-of-life care remains unaddressed.

Finally, there may be a natural progression associated with the implementation of care management programs. For example, some MCOs seek to identify high-risk older persons in order to provide case management and are accustomed to dealing with community-based social services agencies. Such plans may be more likely to address end-of-life care than those that do not engage in these activities. In contrast, MCOs that have not mounted efforts to identify and case-manage high-risk patients or are only beginning to do so might legitimately regard their development as a higher priority than end-of-life care.
LIST OF INTERVIEWEES

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