EXECUTIVE SUMMARY

At the 2004 Annual Meeting, the House of Delegates adopted Resolution 716, which calls for the AMA to gather all relevant information concerning the most expensive 5% of medical patients in order to be able to devise ways to handle these cases less expensively by: using best-management practices; exploring whether “centers of excellence” provide catastrophic care more efficiently; exploring whether consultation from regional or national experts at an earlier time in these high cost cases might provide benefit; earlier consideration of end-of-life issues; and better education about “palliative” medicine. Council on Medical Service Report 5 (A-05) presents detailed data on catastrophic care costs, outlines and evaluates various approaches to cost-containment and quality improvement, and presents several policy recommendations.

Five percent of patients account for approximately half of all health care expenditures in a given year. Aggregate spending for the ten most expensive medical conditions total’s nearly 50% of all health expenditures. Nevertheless, a number of factors limit the feasibility of strategies to contain costs by focusing solely on the most expensive patients or the most expensive conditions. Top-spending patients in a given year generally do not remain in the top-spending group the following year. Most cases of the medical conditions with the highest national costs do not occur among top-spenders, and top-spenders have many disparate, sometimes rare conditions. Further, the reduction of treatment costs at the individual level can lead to higher aggregate costs by increasing the number of people receiving treatment. In addition, high costs very often represent highly valued, appropriate treatment rather than wasteful spending. The dearth of demonstrable cost savings could reflect the fact that program evaluation criteria are usually based on clinical outcomes or quality improvement, or that cost savings might not appear until after the study has ended.

In order to devise more effective strategies to contain health care costs, more detailed information is needed on the relationship between high-cost individuals and the most expensive conditions. The Council believes that cost-containment efforts would be facilitated by greater patient involvement in assessing the tradeoffs between costs and benefits of health services, and by allowing insurers that invest in preventive measures for the long-term to capture more of savings realized. The Council also continues to believe that the AMA proposal for expanding health insurance coverage and choice, combined with the use of health savings accounts and other forms of consumer-directed health care, would help to realign incentives to make patients more cost conscious and to permit greater continuity of coverage, thereby rewarding both patients and insurers for cost-saving decisions and activities.

The Council recommends that, in order to ensure that quality of care is not compromised, the AMA encourage physicians and the medical profession to become more engaged in the development and implementation of cost-containment policies and strategies. The Council also recommends support for additional research into the characteristics of the most expensive patients; and for greater evaluation of the use of various approaches to cost containment and quality improvement so that their immediate and future impacts can be better assessed.
At the 2004 Annual Meeting, the House of Delegates adopted Resolution 716, which calls for the
AMA to gather all relevant information concerning the most expensive 5% of medical patients in
order to be able to devise ways to handle these cases less expensively by: using best-management
practices; exploring whether “centers of excellence” provide catastrophic care more efficiently;
exploring whether consultation from regional or national experts at an earlier time in these high
cost cases might provide benefit; earlier consideration of end-of-life issues; and better education
about “palliative” medicine. The Board of Trustees referred the requested study to the Council on
Medical Service for a report back to the House at the 2005 Annual Meeting.

Despite a recent deceleration, growth in health care spending continues to outpace both inflation
and overall economic growth. In 2003, U.S. health expenditures reached $1.7 trillion, accounting
for 15.3% of Gross Domestic Product (Smith et al., Health Affairs, 2005). A major driver of cost
growth has been technological innovation in the diagnosis and treatment of disease, much of which
has yielded demonstrable benefits. At the same time, the number of uninsured has continued to
rise steadily, and an aging population threatens to strain Medicare’s resources beyond capacity.

Amid these mounting concerns is growing interest in devising ways to contain health care costs and
improve quality of care. The small percentage of the population generating a high concentration of
health care costs is a natural focus for cost-containment efforts. This report presents detailed data
on catastrophic care costs, outlines and evaluates various cost-containment approaches, and
presents several policy recommendations.

THE DISTRIBUTION OF HEALTH CARE COSTS

The Distribution of Costs Across Individuals

It is well-recognized that the distribution of health care costs is highly skewed, with a small portion
of the population accounting for a large portion of total costs in a given year. As shown in Table 1,
there has been remarkable consistency in the distribution of health care costs for a variety of
populations, as illustrated by data from the general and Medicare populations (Berk and Monheit,
Health Affairs, 2001; Olin and Machlin, 2003; and MedPAC Report to the Congress, June 2004):

• The most costly 1% of individuals account for roughly 20-30% of total expenditures;

• The most costly 5% of individuals account for roughly 50% of total expenditures; and
The least costly 50% of individuals account for only 3% of total expenditures.

Table 2 presents a similar picture by looking at the distribution of individuals by expenditure level for the general and Medicare populations (Olin and Machlin, 2003; and Centers for Medicare and Medicaid Services, 2002). About one in six people in the general population had no health care expenditures during the year. Among the general population, the least costly half averaged annual expenditures of about $450, while members of the highest 5% exceeded $8,000. The pattern of distribution is similar in the Medicare population, although the absolute spending levels are much higher. Only one in 20 Medicare beneficiaries had no health care expenditures during the year. Those in the least costly third of the distribution averaged less than $500 in annual expenditures, whereas those in the top 6% exceeded $25,000.

**Transience of High Spending**

The most costly 2-3% of individuals in a given year generally do not remain in the extremely high-cost category in subsequent years. Many have experienced truly unpredictable illness or injury and recover or die by the following year. Thus, cost distributions across individuals become less skewed the longer the time period (e.g., for a given cohort, there is less variation in costs over the course of a lifetime than over a year). Figure 1 illustrates transitions across risk categories over time using data from the Medicare fee-for-service program (MedPAC Report to the Congress, June 2004). Only 28% of the top 1% spenders in a given year remain in that category the following year, with more than 60% dying and 10% falling into a lower spending category. There is more stability over time for broader cost categories, as illustrated by the bottom half of Figure 1. Among the top quarter of Medicare spenders, about half remain in that category in the subsequent year, with 17% dying, and 30% moving into a lower spending category. Similar movements across cost categories have been demonstrated in the general population (University of Michigan Health Management Research Center, 2004; Grazier and G’Sell for the Society of Actuaries Research Project, 2004; Monheit, *Medical Care*, 2003; and Ash et al., *Health Services Research*, 2001).

**The Distribution of Costs by Age and Insurance Status**

Although health care spending varies by income and race, researchers have found age and insurance status to be much stronger determinants of expenditure level (Olin and Machlin, 2003). Figure 2 shows the increase in health care expenditures with age in 1999, averaging under $900 for children to more than $6,000 for the elderly. As shown in the bottom of Figure 2, average expenditure also varied widely by insurance status, from under $700 for the uninsured to more than $8,000 for those enrolled in Medicare and Medicaid (or another public program), with the privately insured falling in between. Within each age or insurance category, the median expenditure is markedly lower than the mean, a further indication of the skewed distribution of health care expenditures within subgroups of the population. Indeed, among the elderly, average costs escalate with age, in 1999 averaging over $11,000 among all elderly but over $20,000 for those 85 and older (Keehan et al., *Health Care Financing Review* Web Exclusive, 2004).

**Costs at End of Life**

Studies have consistently found that, although only 5% of Medicare beneficiaries die each year, care in the final year of life accounts for about a quarter of all Medicare expenditures (Hoover et al., *Health Services Research*, 2002; Buntin and Huskamp, *The Gerentologist*, 2002; Felder et al., *Journal of Health Economics*, 2000; and Lubitz and Riley, *New England Journal of Medicine*, 1993). Between 1992 and 1996, the average cost per Medicare beneficiary was 5 times higher during the last year of life than during non-terminal years ($37,581 vs. $7,365), with spending
concentrated in the last months of life (Hoover et al., 2002). Inpatient hospital costs comprised the largest share of spending for both groups but were more than seven times higher during the last year of life ($15,461 vs. $2,040). After inpatient hospitalizations, nursing home and long-term facility care comprised the largest share of last-year spending. Hoover et. al., emphasize that among institutionalized beneficiaries, average spending was only slightly higher during the last year of life, therefore suggesting that efforts to contain nursing home and long-term care facility expenses target all residents, not just the terminally ill. Hospice care accounts for a small but growing share of Medicare spending (less than 2% in 2001), nearly 90% of which is spent during the last year of life (Centers for Medicare and Medicaid Services, Office of the Actuary, 2002; and Hoover et al., 2002).

The relationship between end-of-life costs and age at death has been the subject of considerable attention, particularly because of the rise in life expectancy. For those dying at an older age, average costs of care in the last year of life may actually be somewhat lower, perhaps reflecting more rapid progression of illness, less reliance on acute care, and less desire to use expensive life-prolonging technology (Shugarman et al., *Journal of General Internal Medicine*, 2004; Hoover et al., 2002; and Felder et al., 2000). The mix of services and funding sources also varies with age at death. Older decedents had higher nursing home and long-term care expenditures, which are financed predominantly privately or by Medicaid. However, Medicare expenditures in the last year of life were found to decline with age of death (Hoover et al., 2002), possibly attenuating the effect of increased longevity on future Medicare costs.

The Distribution of Costs by Medical Condition

As with the distribution of health care costs across individuals, the distribution of costs across medical conditions is also highly concentrated. Thorpe et al. found that 9% of all spending on the treatment of medical conditions in 2000 went to heart disease (*Health Affairs*, 2004). Table 3 shows the ten medical conditions with the greatest national cost burden in 2000. The middle column of the table gives treated prevalence rates by condition, while the last column ranks conditions by per-patient treatment costs. The list includes both chronic and acute conditions which, collectively, represent nearly half of total spending for all medical conditions. High aggregate spending for a condition can arise from a large number of patients being treated for the condition, high per-patient treatment costs, or both. Cerebrovascular disease, which ranks first of the ten conditions in per-patient treatment costs, is only the tenth contributor to aggregate costs owing to its comparative rarity. In contrast, hypertension ranks much lower in per-patient treatment costs (tenth) but has higher aggregate cost (sixth) because it is so common. The most expensive condition in the aggregate, heart disease, does not stand out for its prevalence (sixth) but is associated with high hospitalization rates and high per-patient treatment costs (third), whereas the second most expensive condition in aggregate cost, trauma, is more prevalent but has lower per-patient treatment costs (seventh).

The Thorpe study also looked at 1987-2000 growth in aggregate cost for each condition, finding that both prevalence and per-patient costs increased in nearly all cases. The demographic shift toward an older population underlies some of the overall rise in prevalence rates. The sharp rise in pulmonary conditions is due in part to increased asthma cases, whereas the nearly doubling of mental disorders reflects wider use of antidepressant drugs and reduced stigma of seeking treatment (*Zuvekas, Health Affairs*, 2005). Increased prevalence of diabetes, cerebrovascular disease (mostly stroke), and hypertension mirrors the rise in obesity, which is notable given the high portion of health care expenditures associated with modifiable health risks (Anderson et al., *American Journal of Health Promotion*, 2000). In contrast to the other conditions, prevalence of trauma
declined by 30%, perhaps reflecting the effect of safety legislation and advances in automobile technology.

Increased treatment costs for all ten conditions is associated with technological innovation, and possibly a rise in defensive medicine accompanying the sharp increase in physician medical liability premiums. Some medical innovations reduce per-patient treatment costs, for instance minimally invasive laparoscopic surgeries that reduce pain and recovery times. Although such innovations can reduce per-patient costs and improve quality, they can also increase demand for treatment, thereby driving up aggregate costs for some conditions (Gelijins et al., *Health Affairs*, 2005). The major cost driver was increased prevalence for half of the most costly conditions, and more expensive treatments for the other half. Again, no obvious pattern emerges, suggesting that different conditions are likely to be amenable to different cost-containment strategies, for example targeting a small number of high-cost individuals for intensive case management vs. population-based interventions.

Characteristics of Top-Spenders

Berk and Monheit (2001) found that although age and low health status were associated with being among the top 1% of spenders, a slight majority of top-spenders did not report fair or poor health and were not elderly. Specifically, in 1996 those reporting fair or poor health made up 49% of top-spenders (while representing only 11% of the total population), and the elderly made up 46% of top-spenders (while representing only 13% of the total population). For those under age 65, form of health insurance (HMO, PPO, etc.) was not associated with the likelihood of being a top-sponsor, although the uninsured were underrepresented among top-spenders in part because they receive less care than the insured. Although the most costly 5% of patients have much higher than average rates of diabetes, heart failure, pulmonary disease, and depression, it should be noted that most people with these conditions are not top-spenders in a given year (Ash et al., 2001). Compared to others, top spenders are much more likely to have many comorbidities (Zhao et al., *Disease Management and Health Outcomes*, 2003).

Costs of Medicare Beneficiaries

Among all Medicare beneficiaries, roughly eight in ten have one or more chronic condition (Berenson and Horvath, *Health Affairs* Web Exclusive, 2003), and one in ten resides in a nursing home or other institution (CMS, Medicare Current Beneficiary Survey, 1999). Costly Medicare beneficiaries tend to have multiple chronic conditions, utilize inpatient hospital services, and be in the last year of life (MedPAC Report to the Congress, June 2004). In 2002, one-fifth of Medicare beneficiaries with one or both of just two chronic conditions, congestive heart failure and diabetes, accounted for more than half of all program spending and made up more than 70% of the top 1% of spenders, although not all of their medical expenses went directly to treatment of those conditions. As noted for the general population, many other beneficiaries with those conditions were not top spenders.

As noted in a separate report before the House of Delegates at this meeting (Council on Medical Service Report 2, A-05), the under age 65 disabled represented 15% of Medicare beneficiaries in 2003, with end-stage-renal disease (ESRD) beneficiaries accounting for less than one percent of Medicare enrollment. Average Medicare expenditures are somewhat higher for elderly beneficiaries than the under 65 disabled, $5,961 compared to $4,462 in 2001 (MedPAC Data Book, June 2004). However, including health care costs paid by Medicaid and out-of-pocket reveals that average costs are higher for the disabled than for the elderly, and that a disabled beneficiary has a greater likelihood of incurring costs of $50,000 or more in a year (Riley et al., *Inquiry*, 2003).
Although average annual Medicare spending is much higher among those with ESRD ($29,399) than other beneficiaries, ESRD patients account for only about 5% of program expenditures because of their small numbers (MedPAC Data Book, June 2004).

STRATEGIES TO REDUCE CATASTROPHIC COSTS

Quality Improvement and Cost Containment

There is a great deal of overlap in initiatives designed to contain costs and those designed to improve quality. Frequently, “quality improvement” explicitly or implicitly refers to reduction of per-patient costs, in addition to improvement in pure quality measures such as clinical outcomes or patient satisfaction. Further, cost-containment and pure quality improvement objectives can either be complementary or represent difficult tradeoffs, depending on the specific context. For example, coordination of care might simultaneously support both objectives by eliminating wasteful redundancies or delays in treatment. Some interventions, such as screening for chronic conditions, can have mixed effects on cost and quality. While screening offers patients valuable reassurance and allows early intervention, thus averting future illness and costs, it also can generate additional burdens associated with false-positive results, patient counseling, and other follow-up actions. Thus, it is important to keep in mind that cost-containment strategies may negatively impact quality.

Various strategies to contain costs and/or improve quality can be distinguished along a number of dimensions: the individuals, populations, or conditions that they target; their explicit or implicit objectives; whose behavior they seek to influence (e.g., patients, physicians, other health care providers); the settings in which they are applied; the metrics they use to measure success; and who uses what information and how—for treatment decisions, coverage decisions, benefit mandates, payments, etc. However, a specific program designed to contain costs or improve quality might employ more than one approach. As discussed in a separate report before the House of Delegates at this meeting (Council on Medical Service Report 3, A-05), Medicare is undertaking a number of demonstration projects that address pay-for-performance and disease management programs.

Evidence-Based Medicine, “Best Practices,” and Clinical Treatment Guidelines

Evidence-based medicine is a broad movement that grew out of managed care cost-containment efforts in the 1980s, government and employer desires to stem escalating health care costs, and a growing awareness of the large regional variations in treatment practices and costs not justified by differences in underlying epidemiology or in outcomes (Eddy, Health Affairs, 2005). The movement also was fueled by an explosion of new information and treatments, the widening gap between medical knowledge and its implementation to practice, and increased attention to medical errors (Institute of Medicine, To Err is Human, 1999; and IOM, Crossing the Quality Chasm, 2001). Evidence-based medicine, “best practices,” and clinical treatment guidelines are among a variety of related strategies to contain medical costs and/or improve quality. Evidence-based medicine also has been incorporated into disease management and case management programs.

Although evidence-based medicine has the potential to reduce medical errors and contain costs, it also has some limitations regarding methodology, values, and implementation. Atkins et. al., point out that even when there is consensus about the evidence, there might be disagreement over the implications for patient treatment or public policy (Health Affairs, 2005). Medical treatments with small or uncertain benefits may be highly valued by individual patients and physicians facing illness, whereas insurers and public policy makers responsible for making coverage, funding or public safety decisions must evaluate treatments from the perspective of opportunity costs, societal
risks, and effects on access and equity. The very process of evidence-based medicine includes a bias toward treatments with effects that can be readily observed and quantified, but are not necessarily more effective in the long run (Tanenbaum, *Health Affairs*, 2005). A different difficulty is that findings from highly controlled settings might not hold up under real-world conditions (Kilbourne et al., *Milbank Quarterly*, 2004; and Mendelson and Carino, *Health Affairs*, 2005). Part of the difficulty in translating research into clinical practice is that results are generally reported as averages, which ignore variability in treatment effects across patients (Kravitz et al., *Milbank Quarterly*, 2004).

Individual patient variation raises the question of whether recommended protocols are written or interpreted as strict algorithms or as flexible guidelines. Indeed, physicians value professional autonomy and often resist practicing “cookbook medicine” in lieu of exercising their own clinical judgment. Individual judgment and personalized, flexible treatment approaches may be particularly necessary for complex cases in which patients have multiple conditions (Tinetti et al., *NEJM*, 2004). The state of Minnesota recently set off a firestorm of controversy by passing legislation mandating adoption of best practice guidelines, offering compliant care providers protection against certain malpractice allegations, and permitting state employee insurers and Medicaid to withhold partial payment for non-compliance. From a public policy perspective, reduction of medical practice to rigid algorithms could preclude individual innovations in care, inhibit competition among physicians, and devalue choice and patient preferences (Timmermans and Mauk, *Health Affairs*, 2005; and Gelijns, et al., 2005). Finally, it should be noted that evidence-based medicine could impact physician liability, both by reducing medical errors and by increasing vulnerability if lack of adherence to protocols (or failure to depart from protocols under extenuating circumstances) is taken as evidence of fault.

**Disease Management and Case Management**

Disease management has been described in the AMA Private Sector Advocacy primer *Demystifying Disease Management* (2004) and in Council on Scientific Affairs Report 11 (A-04), “Management of Chronic Disease.” Disease management programs have expanded dramatically over the last decade, most commonly for diabetes, asthma, congestive heart failure, coronary artery disease, high-risk pregnancy, and depression. They rely on prospectively identifying individuals who are likely to incur high costs associated with chronic illness, and who are amenable to interventions designed to lower costs or improve quality. The objective is to intercede before the unhealthy behaviors lead to chronic conditions, or improve the self-management of chronic conditions and prevent complications.

Disease managers, usually nurses, are employed by health plans, disease management companies, pharmaceutical benefit management companies, and occasionally large physician groups. They assist patients through a variety of techniques: health risk assessments; patient education materials; telephone and e-mail contact; telemonitoring devices that transfer data from the patient’s home; group programs to modify unhealthy behaviors; and rate negotiation with service providers. Although disease management programs can provide valuable support to both patients and their physicians, when there is not appropriate communication between disease management representatives and patients’ physicians, there can be a negative impact on patient care and the patient-physician relationship. For example, some disease management representatives have been known to recommend treatment changes directly to patients without consulting the treating physician.

In contrast to disease management, case management focuses on patients with acute conditions, such as by transferring a patient from a high-cost acute care facility to a lower-cost setting. Case
management is sometimes incorporated into disease management programs for chronically ill patients who experience acute episodes or require multiple, expensive services.

In Council on Medical Service Report 3 (I-97), the Council developed detailed principles for the design and evaluation of disease management programs (Policy H-285.944, AMA Policy Database). A key principle is that the primary goal of disease management should be to improve clinical outcomes, with cost savings being a legitimate but secondary objective. The principles stress the importance of involving the patient’s primary or principal care physician in the disease management process as much as possible; assuring continuity of care across different settings; and communication and coordination of care between primary care physicians, specialists, and disease management personnel. Patient participation in disease management programs should be voluntary, and programs should emphasize patient education and empowerment so that patients can more successfully manage their own health and intelligently use care resources.

Disease management programs are developed with the goals of improving quality and reducing cost. Nonetheless, studies of the impact of disease management programs typically focus on short-term outcomes or quality improvements, making it difficult to quantify the impact on health care costs, particularly over time. For example, numerous studies have shown disease management to be an effective tool for improving glycemic control in diabetics (Shojania and Grimshaw, *Health Affairs*, 2005). Although less is known about the impact on spending, it is likely that the improved clinical results translate into averted costs of hospitalization. Hypertension disease management programs appear to have less demonstrable clinical effect. Kaiser Permanente disease management programs for coronary artery disease, heart failure, diabetes, and asthma were found to have substantial quality improvement, but no cost savings (Fireman et al., *Health Affairs*, 2005). Similarly, a recent review by the Congressional Budget Office found insufficient evidence that Medicare disease management programs can reduce the cost of health care services for congestive heart failure, coronary artery disease or diabetes, although other possible benefits were not examined (October 2004). Another consideration in evaluating the impact of disease management on health care costs is the cost of disease management programs themselves, and whether it is ultimately more efficient to develop disease management organizations and infrastructures, rather than directly integrating disease management into existing delivery systems (e.g., by paying physicians’ practices for undertaking disease management activities).

In summary, available evidence suggests that disease management programs can improve quality of care, at least for certain conditions and using short-term outcome measures, but that the overall impact on costs has yet to be demonstrated. The lack of evidence on cost may simply reflect the fact that most studies to date have gathered quality measures rather than cost data, and studies have been too brief to detect longer-term cost savings. It also may be that cost savings are demonstrated by unpublished data collected by insurers and disease management companies.

**Pay-for-Performance Initiatives**

In general, pay-for-performance initiatives aim to improve adherence to treatment guidelines by physicians and other health care providers. A growing number of insurers have developed physician pay-for-performance programs that reward physicians on the basis of their adherence to guidelines. Physicians who achieve specified thresholds of performance (e.g., by following the guidelines) receive bonuses. Process measures such as adherence to protocols are frequently used as a basis for reward because of difficulties in using outcome-based performance measures, including accurately adjusting outcomes to reflect for physician case-mix.
A number of limitations have been identified in using guideline adherence as a basis for physician performance evaluation and incentives (Garber, *Health Affairs*, 2005). Guidelines do not exist for all conditions and often are not written with performance incentives in mind. Well-written guidelines usually leave physicians considerable discretion, but such flexibility poses challenges for determining adherence. Further, physicians may be penalized for factors beyond their immediate control, such as patient acuity/case-mix, patient adherence to prescribed actions, or actions of other physicians or health care providers involved in the case.

To date, few pay-for-performance programs have been assessed for their impact on cost containment or quality improvement objectives. In March 2005, the AMA released a set of principles and guidelines for pay-for-performance programs that were developed by a special Board/Council Task Force. The five AMA principles state that pay-for-performance programs should be designed and implemented to: (1) ensure quality of care; (2) foster the patient-physician relationship; (3) offer voluntary physician participation; (4) use accurate data and fair reporting; and (5) provide fair and equitable program incentives. The AMA believes that pay-for-performance programs that are primarily designed to improve the effectiveness and safety of patient care may serve as a positive force in our health care system. These principles recognize, however, that physicians should not be penalized for exercising sound clinical judgment in variance with guidelines, and must be given the opportunity to review and appeal program results.

A separate report before the House of Delegates at this meeting (Board of Trustees Report 5, A-05), presents AMA principles and guidelines for pay-for-performance programs.

End-of-Life Care

The idea that limiting intensive care at the end of life can result in sizeable savings is intuitively appealing. On the one hand, Dartmouth researchers have found threefold regional variation in the likelihood of being admitted to an intensive care unit (ICU) toward the end of life, differences that are neither explained by underlying health differences nor associated with different outcomes ([http://www.dartmouthatlas.org/atlas/w6513.pdf](http://www.dartmouthatlas.org/atlas/w6513.pdf)). On the other hand, considerable evidence suggests disappointingly small aggregate savings from shifting terminal patients to lower-cost settings (Luce and Rubenfeld, *American Journal of Respiratory and Critical Care Medicine*, 2002; Emanuel, *JAMA*, 1996; and Chernew et al., *Health Affairs*, 2004). For example, it is difficult to predict who can be saved by treatment and who is at the end of life. One study of ICU patients showed that among the most expensive 10%, two-thirds survived (Welton, *American Journal of Critical Care*, 2002).

Studies of potential cost-savings from hospice care have been inconclusive (Buntin and Huskamp, 2002). Only two studies have randomly assigned patients to hospice and control groups, finding little to no difference in end-of-life costs (Hughes et al., *Health Services Research*, 1992; and Kane et al., *The Lancet*, 1984). A more recent study of hospice care across settings (hospital, home, nursing home) did not appear to lower end-of-life costs, except for cancer patients (Emanuel et al., *Archives of Internal Medicine*, 2002). Given that hospice care currently accounts for less than one in five of terminally ill beneficiaries (Hogan et al., *Health Affairs*, 2001), it is possible that potential cost savings have yet to be demonstrated. In any case, researchers do not expect greater use of advance directives, hospice care, and related measures to increase end-of-life costs. Furthermore, such measures have been found to improve quality by enhancing palliative care, providing better coordination of care, reducing the likelihood of dying in the hospital, and increasing patient autonomy (Luce and Rubenfeld, 2002; and Emanuel, 1996).
“Centers of Excellence” and Regionalized Care Centers

The Centers of Medicare and Medicaid Services, as well as some private insurers, have supported the development and study of “centers of excellence” and similar regionalized care centers focusing on specific conditions. Such centers, sometimes housed in departments of academic medical centers, aim to develop high-quality, cost-effective diagnosis and treatment of conditions that are rare, complex, and expensive (e.g., organ transplantation), or for which there is a great deal of variation in quality and cost of treatment (e.g., cancer, heart disease, infertility, joint replacement; Robinson, *Health Affairs*, 2004). A recent *New England Journal of Medicine* commentary concluded that, to date, there is insufficient evidence of quality or cost benefits from regionalization of the treatment of acute coronary syndromes, although possible benefits may not yet be documented (Rathore et al., 2005). Other studies suggest that hospitals and facilities that perform high volumes of high-risk procedures such as coronary artery bypass grafts (CABG) have better outcomes and quality (e.g., Dimick et al., *Health Affairs*, 2004). A further complication in evaluating the effects of centers of excellence is that even among such centers, there may be wide variation in intensity of care, quality of care, outcomes, and costs (Fisher et al., *Health Affairs*, 2004). Given that many patients do not have geographic or financial access to centers of excellence, the biggest potential advantage of centers of excellence may be in developing best practices to be disseminated more widely.

RELEVANT AMA POLICY


As previously discussed, Policy H-285.944 provides detailed principles for the design and evaluation of disease management programs. There are also numerous other policies on disease management (Policies H-140.919, H-160.938, H-285.921, and H-285.956[5]), and case management (Policies H-200.969[4], H-285.998, H-290.982[3], H-290.985[13], H-290.995, and H-360.989). Finally, the AMA also has a number of policy and ethical opinions on end-of-life and palliative care, which support appropriate end-of-life care, including shifting the focus of care from the “futile” prolongation of life to palliative care (Policies H-55.999, H-85.962, H-85.966, H-140.966, H-295.884, E-2.035, and E-2.071, and E-8.20).
DISCUSSION

As the data in this report suggest, 5% of patients account for approximately half of all health care expenditures in a given year. The aggregate spending for the ten most costly medical conditions totals nearly 50% of all health expenditures, as well. However, less is understood about the extent to which these costs overlap. Overlapping costs represent potential “low-hanging fruit,” in terms of opportunity for cost savings, whereas it may be more difficult to target costs diffused across a large number of individuals and medical conditions.

As a result, the Council believes that knowing more about the relationship between high-cost individuals and high-cost conditions would help decision-makers determine the likely effectiveness of focusing on high-cost conditions rather than high-cost individuals. On the one hand, high-cost patients disproportionately have high-cost conditions and multiple comorbidities. On the other hand, the majority of cases of conditions with high aggregate costs are not found among top-spenders, and today’s top-spenders will not necessarily be tomorrow’s top-spenders. What is less known is the extent to which costs of top spenders arise from a variety of less common, disparate conditions (e.g., hemophilia, central nervous system infections). This possibility is hinted at by the fact the ten most costly types of hospital stays include only about half of the conditions that are most costly in the aggregate (Elixhauser et al., AHCR, 2000).

In practice, costs of specific individuals or conditions are not necessarily amenable to reduction even when readily predicted or identified. How amenable costs are to cost-containment is a question of both technical feasibility and the value individuals and society place on the care in question. High-cost conditions may represent highly valued treatment rather than opportunities to reduce wasteful spending (Druss et al., Health Affairs, 2002). A growing body of research has found that innovations in the treatment of heart disease, cancer, premature birth, cataracts, and depression have yielded benefits far in excess of their costs (e.g., Cutler and McClellan, Health Affairs, 2001). In particular, new approaches to heart disease, the single most costly condition, have sharply reduced death rates, suggesting that wider use of such treatments is appropriate if costly (Thorpe et al., 2004).

Several dynamics of cost trajectories over time must be taken into account as well: the effect of an intervention on future costs of the individual patient; the effect on future aggregate costs; and the tradeoffs between focusing on immediate costs versus research and development in order to lower costs in the future (e.g., through better understanding of how to stem the increased prevalence of asthma). Recently, researchers have drawn renewed attention to the childhood origins of adult health status, maintaining that many common chronic conditions have modifiable risk factors that arise in childhood (Forrest and Riley, Health Affairs, 2004). As noted earlier, innovations that reduce treatment costs at the individual level can lead to higher aggregate costs, for example laparoscopic surgical techniques and the use of antidepressants. The case of HIV/AIDS illustrates the influence of both prevention and research on costs over time. The development of expensive antiretroviral drug therapies drove up immediate per-patient treatment costs but paid off in the long run by reducing even more expensive hospitalizations, not to mention increasing quality and length of life and slowing transmission (Bozzette, NEJM, 2005).

A major challenge for preventive interventions is the misalignment of financial incentives. In particular, the further out into the future any cost savings of prevention are realized, the less likely it is that an insurer will capture the savings. Proponents of consumer-driven health care maintain that placing greater financial responsibility for health care expenditures on individual patients will provide incentives to them to adopt healthy lifestyles and invest in other cost-saving measures. Similarly, shifting ownership and selection of health insurance from employers to individuals...
would allow greater continuity of coverage, thereby rewarding health plans with greater return on
investment in interventions that reduce or forestall future costs. Finally, another consideration in
designing cost-containment efforts is the fact that costs may be funded by multiple payers. For
instance, shifting the site of custodial or end-of-life care could reduce Medicare expenditures while
increasing Medicaid expenditures, out-of-pocket expenditures, or the burden on family members.

CONCLUSIONS

With the continued growth of national health care expenditures, it is natural to focus cost-
containment efforts on the most expensive 5% of patients, who account for approximately one-half
of all health care spending. Based on the data analysis in this report, the Council believes that
focusing strategies on top-spenders as a means of containing health care costs continues to have
merit. Nevertheless, the Council believes that it is important to draw attention to a number of
factors that limit the feasibility or effectiveness of strategies that are limited solely to top-spenders:

• Most cases of those medical conditions with the greatest national cost burden are among
  patients who are not top-spenders.
• Most top-spenders in a given year do not remain in the top-spending group the following year.
• Top-spenders have many disparate, sometimes rare conditions (although more information is
  needed on characteristics of top-spenders).
• Reduction in per-patient treatment costs can lead to an increase in national spending by
  increasing the number of people receiving treatment.
• Some cost-containment resources should be invested elsewhere, such as prevention and
  research, in order to lower future costs.
• High costs very often represent highly valued, appropriate treatment rather than wasteful
  spending.

As discussed in this report, a number of approaches have been devised to contain costs and
improve quality, including evidence-based medicine; the use of “best practices” treatment
guidelines; disease management, case management, and pay-for-performance programs; improved
end-of-life care, and “centers of excellence.” In general, the Council’s review of such strategies
and programs reveals the following:

• Although most programs appear to have the ability to improve the quality of patient care at
  some level, they have not, in the aggregate, demonstrated clear cost savings. An exception to
  this general conclusion appears to be hospice care for cancer patients.
• The dearth of demonstrable cost savings might reflect the fact that program evaluation criteria
  are usually based on clinical outcomes or quality improvement, and that any corresponding
  cost savings might be delayed until beyond the study period.
• The longer the delay between preventive measures and the realization of cost-savings, the
  weaker the incentive for an insurer to cover such measures.
Cost-containment efforts must be balanced and take into account factors such as quality of care, the patient-physician relationship, the need for appropriate departures from treatment protocols, and coordination and communication among various parties.

Existing information on the distribution of health care costs and characteristics of high-cost patients points to a number of complexities and gaps in knowledge. In order to devise more effective strategies to contain health care costs, the Council believes that more information is needed on the detailed breakdown of, and variation within, cost categories, as well as the intersection of high-cost individuals, conditions, and services. The Council also believes that cost-containment efforts would be facilitated by greater patient involvement in assessing the tradeoffs between costs and benefits of health services, and by allowing insurers that invest in preventive measures for the long term to potentially capture more of any savings. Finally, the Council continues to believe that the AMA proposal for expanding health insurance coverage and choice, combined with the use of health savings accounts and other forms of consumer-directed health care, would help to realign incentives to make patients more cost conscious and to permit greater continuity of coverage, thereby rewarding both patients and insurers for cost-saving decisions and activities.

RECOMMENDATIONS

The Council on Medical Service recommends that the following be adopted and the remainder of the report be filed:

1. That, in order to ensure that quality of care is not compromised, the AMA encourage physicians and the medical profession to become more engaged in the development and implementation of cost-containment policies and strategies, particularly those directed toward high-cost patients. (Directive to Take Action).

2. That the AMA support additional research into the characteristics of the five percent of the patient population with the highest health care costs. (Directive to Take Action)

3. That the AMA support greater evaluation of the use of disease management, case management, pay-for-performance, and end-of-life care programs for high-cost patients, so that their cost-containment impact and projected future saving can be better assessed. (Directive to Take Action)

4. That the AMA continue to inform the medical profession and the general public regarding issues impacting catastrophic care costs and the complexities therein. (Directive to Take Action)

References for this report are available from the AMA Division of Socioeconomic Policy Development.

Fiscal Note: Continue to educate the medical profession and public and support additional research and evaluation of strategies to contain catastrophic care costs at an estimated total cost of $2,477.
### Table 1. Distribution of Health Expenditures Across Individuals for Selected Years

<table>
<thead>
<tr>
<th>Percent of Population Ranked by Expenditures</th>
<th>General Population (inc. Medicare)</th>
<th>Medicare</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top 1 percent</td>
<td>17%</td>
<td>27%</td>
</tr>
<tr>
<td>Top 2 percent</td>
<td>-</td>
<td>38</td>
</tr>
<tr>
<td>Top 5 percent</td>
<td>43</td>
<td>55</td>
</tr>
<tr>
<td>Top 10 percent</td>
<td>59</td>
<td>70</td>
</tr>
<tr>
<td>Top 30 percent</td>
<td>-</td>
<td>90</td>
</tr>
<tr>
<td>Top 50 percent</td>
<td>95</td>
<td>97</td>
</tr>
</tbody>
</table>


### Table 2. Distribution of Individuals by Level of Health Expenditures

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percent of Population</td>
<td>Level of Medicare Expenditures</td>
</tr>
<tr>
<td>None</td>
<td>15.7%</td>
<td>None</td>
</tr>
<tr>
<td>$1-$1,000</td>
<td>49.9</td>
<td>$1-$499</td>
</tr>
<tr>
<td>$1,001-$2,000</td>
<td>12.6</td>
<td>$500-$1,999</td>
</tr>
<tr>
<td>$2001-$3,000</td>
<td>6.2</td>
<td>$2,000-$4,999</td>
</tr>
<tr>
<td>$3,001-$4,000</td>
<td>3.6</td>
<td>$5,000-$9,999</td>
</tr>
<tr>
<td>$4001-$5,000</td>
<td>2.6</td>
<td>$10,000-$24,999</td>
</tr>
<tr>
<td>$5,001-$6,000</td>
<td>1.9</td>
<td>$25,000 and more</td>
</tr>
<tr>
<td>$6,001-$7,000</td>
<td>1.3</td>
<td></td>
</tr>
<tr>
<td>$7,001-$8,000</td>
<td>1.1</td>
<td></td>
</tr>
<tr>
<td>Over $8,000</td>
<td>5.2</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1. Transience in High Spending Among Medicare Beneficiaries


Note: Includes Medicare fee-for-service (FFS) beneficiaries only. Base years are pooled from 1996 to 1998.
Figure 2. Variation in Health Care Expenses by Age, Insurance Status, 1999


Note: Excludes institutionalized and military populations.
Table 3. Ten Most Costly Medical Conditions (2000)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Aggregate Spending ($ millions)</th>
<th>Treated Prevalence (per 100,000)</th>
<th>Rank</th>
<th>Per-Patient Spending Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart Disease</td>
<td>56,679</td>
<td>6,226</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Trauma</td>
<td>41,124</td>
<td>12,338</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Cancer</td>
<td>38,902</td>
<td>3,348</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Pulmonary Conditions</td>
<td>36,477</td>
<td>15,526</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Mental Disorders</td>
<td>34,439</td>
<td>8,575</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Hypertension</td>
<td>23,395</td>
<td>11,382</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Diabetes</td>
<td>18,288</td>
<td>4,260</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Arthritis</td>
<td>17,686</td>
<td>6,966</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Back Problems</td>
<td>17,451</td>
<td>5,092</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Cerebrovascular Disease</td>
<td>14,939</td>
<td>854</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td><strong>Subtotal of Top 10 Conditions</strong></td>
<td>299,380</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total Spending</strong></td>
<td>627,900</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Top 10 as % of Total</strong></td>
<td>48%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Adapted from Exhibit 2 of Thorpe, Florence, and Joski, Health Affairs Web Exclusive, August 2004, which analyzes data from the 2000 Medical Expenditure Panel Survey, Household Component (MEPS-HC).

Notes: Excludes institutionalized and military populations. May overstate spending for some medical conditions because of double-counting of costs of patients with comorbidities. Per patient spending ranks were derived by dividing aggregate spending for each condition by the prevalence rate.