Accounting for the Costs of Caring Through the End of Life

Cost Accounting Peer Workgroup Recommendations to the Field
In 1997, The Robert Wood Johnson Foundation launched a national program Promoting Excellence in End-of-Life Care with a mission of improving care and quality of life for dying Americans and their families. We soon realized that the metaphor of a jigsaw puzzle seemed apt in describing our efforts to expand access to services and improve quality of care in a wide range of settings and with diverse populations. No single approach would suffice—a variety of strategies, models of care and stakeholders are necessary to successfully complete the picture. This monograph represents one aspect of our work and one piece of the puzzle of ensuring that the highest quality of care, including palliative care, is available to all seriously ill patients and their families.

Acknowledgements
This publication was produced by Promoting Excellence in End-of-Life Care, a national program office of The Robert Wood Johnson Foundation, directed by Ira Byock, M.D.

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Special thanks to Karyn Collins for editing the report and to Keila Szpaller for assistance editing.

About the Artist
Much of M.C. Escher’s art is based on mathematical principles. In 1954, he sought out the mathematician H.S.M. Coxeter at a mathematics conference. Coxeter’s work about shapes in multi-dimensional space inspired Escher’s Circle Limit series. After Escher’s death, Coxeter published a paper proving that Escher’s “Circle Limit III” (cover) is mathematically perfect.

Visit the comprehensive Web site of Promoting Excellence in End-of-Life Care for more information on innovative demonstration projects dedicated to long-term changes to improve health care for dying people and their families: http://www.promotingexcellence.org or contact:

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January 2004
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The Cost Accounting Report and Appendices are available at www.promotingexcellence.org

M.C. Escher’s “Sphere Surface with Fish.” © 2003 Cordon Art B.V. Baarn, Holland. All rights reserved.
INTRODUCTION

Attention to care for dying Americans is capturing the interest of policy-makers, health care professionals, patients and the general public. In addition, demographic trends toward larger numbers of elderly with longer life expectancies are reinforcing a new national health policy concern with end-of-life care. Demonstration projects to improve care for dying Americans have produced many successes in recent years across the country. In response, new palliative care programs that complement traditional hospice care are emerging in a variety of settings, and changes in health policy are being proposed that will encourage the concurrent provision of palliative care and curative care.

While initiatives such as those funded by The Robert Wood Johnson Foundation and the United Hospital Fund’s Hospital Palliative Care Initiative are contributing to a greater understanding of issues around quality of care and access to end-of-life care, there is less progress toward predicting and estimating the costs of new initiatives and interventions. At the same time, accurate cost data are critical to policy-makers, who are often faced with balancing trade-offs between access, quality and cost, and for health care administrators and providers who are frequently asked to justify programs to funding sources.

Understanding costs is imperative as costs may in part determine which interventions are widely disseminated and promoted. But the complexities of costs, different accounting systems and even different cost definitions have become obstacles to cost analysis of new projects and cost comparisons across programs. Few studies document the costs and cost effectiveness of palliative and end-of-life care programs or the impact of serious illness on patients’ families. Yet cost pressures in the current health care environment present a compelling reason for accounting for the costs of care during the last phase of life. Studies of Medicare data show that a large percentage of an individual’s total lifetime cost of care is consumed within the last year or two of life. And patients who are informed about the benefits of palliative care, including attention to pain and symptom management, comfort and quality of life, are asking for a higher standard of care that includes palliative care.
The lack of sound and consistent cost accounting methods has impeded attempts at answering fundamental questions, such as:

- How do we evaluate programs offering concurrent palliative and curative care, and assess the costs of end-of-life care in these programs?
- Will improvements in the care for dying patients, including earlier introduction of palliative care and hospice care “upstream” in a patient’s disease, result in decreased health care costs?
- Is the concurrent provision of life-prolonging care and palliative care cost effective, cost neutral or more costly than the current prevalent “either-or” model of care?

Recognizing the critical need for answers to these questions, for more accurate cost measures and consistent methods for evaluating innovative end-of-life programs, Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation, formed the Cost Accounting Peer Workgroup. Convened in the fall of 2000, the diverse group of economists, clinicians, health policy researchers and program managers was charged with identifying accurate and meaningful methods of measuring end-of-life health care resource use and costs. Workgroup members identified specific guidelines, cost methodologies and measurement tools for analyzing costs of end-of-life care, and developed the recommendations put forth in this report for resolving problems and issues in health care cost accounting through the end of life.

These recommendations are addressed to individuals and organizations involved with or providing end-of-life care: program developers who are designing cost effective interventions; agencies and institutions developing new, innovative projects or modifying existing programs; foundations, professional associations, and state and local partnerships who are working to improve end-of-life care for dying Americans; and professionals involved with performing and providing support for cost analyses.

**Challenges in Assessing the Costs of Palliative and End-of-Life Care**

The following list of cost measurement issues reflects the unique challenges that arise when evaluating characteristics of end-of-life care and the innovative programs developed to provide that care. The list first addresses issues in designing the cost evaluation and then issues in computing costs. Workgroup recommendations follow each topic discussed.

In developing this set of concerns, Workgroup members focused primarily on resources and economic costs within different health care delivery systems that have some initial data available for developing cost accounting practice standards (direct health system and program costs). This approach does not take into account social cost trade-offs or indirect costs, including economic losses to family caregivers and the societal costs of lost productivity of family caregivers.

**Issues in Designing the Cost Evaluation**

**Plan Early and Fit Accounting Methods to Programmatic Interventions.**

Most palliative and end-of-life care programs are tightly budgeted and many are demonstrations that may be funded for a limited period of time. Consequently, cost evaluation may not be feasible if it is added as an afterthought when the program is well underway or a demonstration project is nearly concluded. Even when evaluations are planned early in a project, the analysis proposed may be too ambitious to complete with the time and resources available.

Often clinical researchers do not involve economists in designing the program evaluation, or may interact too infrequently with clinical
leaders and staff to understand the population served or the services delivered. Resulting inadequacies in the data gathered and its analysis may fail to produce meaningful findings about an intervention.

Recommendations

- **Plan the cost analysis before the clinical or health service delivery palliative or end-of-life care project begins, or for ongoing programs, at least one year before results are expected.**
- **Include clinical and evaluation personnel, program managers and economists in the project planning process.**

**Plan the sample size.**

It is important to plan the sample size in each arm of the study. Many palliative and end-of-life care demonstration programs do not serve enough patients to permit statistical comparisons of outcomes with patients in the control or comparison group. The number of “evaluable” patients in programs with larger enrollments can shrink quickly, sharply reducing statistical power to detect program effects on key outcome variables.

The sample size may be affected by: 1) the number of patients enrolled in the program or assigned to the control or comparison group; 2) the number of these patients who die; 3) time of death relative to study entry; 4) the period of time during which patients are accrued; 5) the anticipated cost difference associated with the program; and 6) the distribution of costs in the study and control or comparison groups.

Recommendations

- **Outline tasks involved in the proposed evaluation; and**
- **Plan adequate sample size for valid cost comparisons.**

**Identify the perspective for cost analysis.**

The costs of care during the last phase of life can be assessed from different perspectives. The fact that a cost evaluation is being conducted from one particular perspective does not make it “wrong.” However, the language and interests of the stakeholders being served will affect the questions addressed, the data collected, the analyses completed and the conclusions reached. If the perspective for a cost analysis is not clearly defined, evaluators may include cost elements that are not relevant to the affected party, and other stakeholders may misinterpret results or apply them inappropriately.

Examples of different perspectives include: perspectives of patients and their families (first party); physicians, hospitals, community health programs and other service providers of a managed care plan (second party); private insurers, Medicare, Medicaid or other payers (third party); employers or other plan sponsors (fourth party); or society as a whole. The perspective used for defining costs affects how costs are measured in practice.

Patients and their family members might define costs in terms of personal, out-of-pocket expenses for health insurance coverage and co-payments, the more intangible costs of purchasing or not purchasing uncovered services or the costs of unpaid caregiving. Agencies providing care may define costs in terms of billed services or a negotiated per diem rate, while third party public and private insurers may consider only those costs that they reimburse or the costs of capitated per member, per month payments. Policy-makers may focus on the costs of funding a program versus alternative uses of these resources. Health plan administrators, policy-makers and advocates need data on the costs of delivering a program to beneficiaries in various markets, ideally from a cost perspective of providing services on an individual basis and for all individuals within a group. If a specialized pallia-
tive or end-of-life care program is included in a bundle of services provided as an employee benefit, employers are concerned about the costs of coverage as well as potential savings from reductions in employee absenteeism and turnover related to family caregiving needs.

Evaluating program costs from a social perspective involves comprehensively assessing the costs of all health care resources utilized regardless of source, as well as opportunity costs and uncompensated costs of family caregiving. Costs of unpaid caregiving, both to employers and to family members and friends, are becoming increasingly important in the policy arena. Caregiver costs include not only unpaid time and effort devoted to a loved one’s care, but also commonly include “opportunity costs” of foregone earnings, loss of health insurance, life insurance and retirement benefits. Associated caregiver stress can result in increases in morbidity (and mortality) and costs associated with health care utilization by caregivers. The data required for such analysis are neither readily available nor easily collected, but such a full analysis is important in determining whether a program that appears to reduce costs for one stakeholder has merely shifted them to others.

Predictably, the accounting perspective of a cost analysis derives from the intended use or purpose of the study. An agency such as a hospice or palliative care organization that provides specialized care to dying patients likely will be interested in the costs of delivering its services compared to projected revenues. In assessing the overall financial impact of a new program (to determine long-term sustainability of the program and decide whether or not to maintain, expand or discontinue specific component services and staffing levels) the program’s impact on total health services utilized and on system efficiency may be considered. When two or more agencies have collaborated in the development and delivery of a palliative or end-of-life care program, partners are likely to be more interested in costs to their particular organization than in an analysis of total costs. Results may indicate the need for an adjustment in resource contributions or renegotiation of how capitated health plan payments are apportioned in managed care risk-sharing arrangements.

**Recommendations**

- Clearly identify and articulate the purposes of a cost evaluation and the stakeholder perspectives from which it is being conducted.
- Employ methods appropriate to the stated purposes and perspectives, and commensurate with the evaluation staff’s time and available resources.
- Identify and discuss the ways in which a programmatic health service delivery model may shift costs among payers, among health care providers or to patients or families, even if estimating the extent of cost shifting falls outside the scope of the evaluation framework. This will enable those who use cost data to better evaluate claims of “cost savings,” and allow policy-makers to decide whether this type of cost shifting is in the public interest.

Clearly describe the palliative or end-of-life care program being studied.

Cost analyses often devote minimal attention to describing the health service delivery programs whose costs and financial outcomes are being assessed. However, because palliative and end-of-life care programs differ in structure, staffing, component services, admission criteria, and the populations they serve, the costs and outcomes of a specific programmatic model of care may not accurately represent those of another. For example, palliative and end-of-life care programs based in hospitals, skilled nursing facilities, outpatient settings and prisons are likely to incur different costs because they serve different populations, provide different packages of services and deliver them in different ways. Similarly, the design, requisite costs and financial outcomes of a palliative and end-of-life care program in a fee-for-service environment are likely to vary from one based in an environment of prepaid (and capitated) health care.

Hospice is a defined programmatic model for delivering palliative care at the end of life. Yet even hospices differ in the populations they serve,
as well as in the range of services and quality of care they provide. An analysis of costs incurred in delivering the Medicare Hospice Benefit may not apply to estimating the costs of caring for adults under age 65 or of dying children and their families. Hospice costs and financial outcomes may not apply to programs that provide concurrent palliative care and life-prolonging treatments. Different interpretations and meanings ascribed to the terms “palliative care” and “hospice” further complicate comparisons of programs and their outcomes.

Unless a cost analysis clearly describes salient features of the clinical and health service delivery program being evaluated, results may be inappropriately generalized or used in misleading comparisons. Nevertheless, experts have different opinions about how programs should be described. Some researchers advocate identifying each component of care to facilitate the creation of different service “packages” tailored to the needs of subgroups of patients and the realities of care delivery in different settings. Other authors fear that if program services are unbundled, Medicare and other payers will analyze the itemized costs of each component of care and decline to pay for some components. These may include “low-tech,” psychosocial services that are central to quality palliative and end-of-life care programs, but more difficult to directly attribute to measurable impacts on health services, pharmaceuticals or durable medical use.

Recommendation

• Describe at least the following features of the palliative and end-of-life care program being evaluated:
  • The context of financing and the larger health service delivery system in which the program is located;
  • The target population of care, including basic demographics and criteria for program enrollment and/or the selection of individuals for enrollment;
  • The specific bundle of services provided, and whether these itemized services substitute for or complement other existing services;

Typical Features of Palliative Care in Promoting Excellence Projects

1. Ongoing communication among patients, families and providers
2. Advanced care planning and patient-centered decision making that is iterative and reflective of patients’ values and preferences
3. Formal assessment and treatment of physical and psychosocial symptoms
4. Care coordination (also known as case management) to streamline access to services and monitor quality of care
5. Spiritual care
6. Anticipatory guidance in coping with illness and issues of life completion and life closure
7. Crisis prevention and early crisis management
8. Bereavement support
9. An interdisciplinary team approach to care
10. 24/7 availability of a clinician knowledgeable about the case
Sources of payment for the service bundle or its components;
When, how and by whom services are delivered;
Whether each component service is available to each program enrollee or whether additional criteria apply to specific services within the palliative and end-of-life program;
Other services patients or families receive that are provided outside the program being evaluated;
The providers and payers of non-program services; and
Criteria for patient discharge or transfer.

Identify appropriate comparison groups.

Although double-blinded randomized controlled trials (RCT) are the gold standard for clinical and health service delivery research, the RCT design may not be feasible or ethically appropriate for some palliative and end-of-life care programmatic settings.

Health plan and agency administrators, physicians and others may not agree to randomization because they are committed to providing equal access for all patients eligible for a program or service. Patients and their family members also may refuse randomization either because they want – or do not want – to be served by a palliative and end-of-life care program. Even if these obstacles can be overcome to accomplish randomization, participants in the evaluation are likely to know whether they are assigned to the treatment or control condition.

When randomization is not possible, it is important, although challenging, to define an appropriate, comparable group of patients who are not enrolled or otherwise receiving the palliative and end-of-life services. Groups of enrolled and not enrolled patients may differ in diagnosis, illness severity, acceptance of approaching death, caregiver resources and many other characteristics that affect utilization and costs of health services. A common practice is to use historical controls, e.g., “We’re spending 10 percent less this year than last year.” However, such analyses can be misleading because both the mix of patients served and the costs of care may change over time. Further, a Hawthorne Effect, the phenomenon of something changing simply because it is being observed, may result if prior year data collection occurs without knowledge that a program will be evaluated.

Recommendations

- If possible, randomly assign eligible patients to receive or not receive the services of the palliative or end-of-life care program and evaluate relevant characteristics of the resulting groups.
- When randomization is not feasible:
  - Identify a group that is reasonably comparable in terms of demographic and clinical characteristics that are likely to impact care and costs;
  - Collect data on resource utilization for a defined period, such as six months, before the start of the cost analysis;
  - Assess the program and comparison groups on case mix and pre-intervention utilization of health services; and
  - Adjust observed costs for differences between program and comparison groups.

Define the period of care to be studied.

In clinical research, estimates of the time required for patients being studied to respond to their treatment usually define the period for assessing related costs. However, differences in the trajectory of disease and the uncertainty of death complicate definition of the time period for cost analyses of palliative and end-of-life care programs. No consensus has been reached on when “the end of life” begins. From a purely scientific perspective there are advantages to retrospectively comparing all costs during a crisply defined period, such as the last year of life. Yet health service delivery must function in real time and respond to the clinical needs of patients and their families. Patients’ functional status, disease trajectory, experienced needs and health care choices are highly individual. It is, therefore, not possible to prospectively determine when the last year of life begins.
Within the category of palliative and end-of-life programs there is significant variability of populations being served and programmatic settings, services and interventions. Some programs are designed and best suited to hospital and ICU settings and focus on the last weeks, days or even hours of life. Others are designed for assisted-living, nursing home or private residential settings and focus on the last months or years of life.

Within a single program, patients do not enter it at the same interval preceding death. The reasons are many. Prognosis is inherently difficult and uncertain, particularly for conditions other than solid tumors. Physicians may be reluctant to refer patients to palliative care or hospice programs when admission criteria are based on prognosis. Denial of the approach of death by physicians, patients and family members also may deter both the timeliness of referrals and their acceptance.

While in the abstract, measuring program costs for an arbitrary time period might appear to be the logical solution, in actuality the length of stay in palliative care programs tends to be highly variable. Confounding factors include the fact that some patients may die too soon after admission for the intervention to have had a significant effect, and others may die before a given study’s end-point is reached. Alternately, some patients will live beyond the designated evaluation end-point so that the full impact of the program and its interventions of the costs of their care at the end of life cannot be captured. (Yet it is possible that their longevity may indicate that these patients have been helped the most by the program’s services.) Patients also may be discharged because they become medically stable, move or change their health insurance. Simple comparisons of costs incurred by patients in the program and control or comparison group during an arbitrary time period are likely to be flawed by uneven exposure to the intervention in the program condition, differences in patient survival and missing data in both the treatment and control or comparison arms of the study.

Additional accounting challenges arise from the knowledge that resource consumption is not spread evenly over whatever time frame is selected for the cost analysis. Palliative care is often more intense during the inception of specialized care and during the final days of life. Evaluation should include both of these periods. Although costs of admission to a program tend to be relatively fixed, they rise to represent a disproportionate amount of total costs when length of service is very brief. Hospice experience demonstrates that this situation can severely challenge providers who are reimbursed at fixed per diem rates. From a methodological perspective, if many patients are enrolled in a program only briefly, the calculated average costs of service per patient or per unit of time may be higher than actually experienced for patients served for a longer period. Moreover, because intake costs are not incurred for patients in the control or comparison condition, a specialized palliative and end-of-life program that serves patients for only brief periods may appear to cost more than usual care, not because of faulty program design, but because of insufficient time to realize potential cost advantages.

A crescendo of pain and other distress during the last days of life also requires an intensification of services. Costs therefore are greater for patients who die in the program than for those who do not. Transfers may occur to improve quality of care, but they also represent intentional or unintentional cost shifting. For example, nursing homes and oncology clinics may send dying patients to the hospital or to hospice, and some “upstream” palliative and end-of-life care programs identify transfer to hospice as their desired outcome.

Recommendations

- Define eligibility criteria, including if applicable, when “end of life” begins in the program being studied.
- Collect data prospectively from a defined entry point both for patients enrolled in the
program, and for the patients in the control or comparison group.

- Report *a priori* assumptions about the time required for the programmatic intervention(s) to demonstrate an effect, and consider excluding from analysis patients who die in less time (e.g., within one week or one month).
- Report on the time during program intake and the final days of life, and examine potential confounding effects of short length of service.
- Analyze data retrospectively from time of death for multiple time periods appropriate to the palliative and end-of-life care program and the evaluation question (e.g., admission and initial phase of care, steady-state care, active dying).
- Conduct two types of analysis: one analysis should include all patients enrolled in the program; the other should include patients who die during or before each period of cost assessment, as well as patients who are discharged from the program prior to death.

**Issues in Computing Costs**

**Identify the units of health care services.**

In most standard economic evaluations, costs reflect the total resources utilized in the output produced; that is, the manufacture of goods or the provision of services provided. This is not usually the case in health care, nor in palliative and end-of-life care, because it is unclear what constitutes the units of service or output. With the exception of component product-services such as laboratory or radiological testing, or discrete services such as outpatient procedures, the provision of health care consists of a range of services. Moreover, as much as it has been attempted, these services are not directly or easily translated into one type of output, such as improved health status, alleviation of illness and symptoms, or increases in quality adjusted life years.

As a result, existing accounting systems do not identify and track many resources and component costs of service delivery (i.e., wages and salaries, number of personnel needed to deliver a “unit of health care service,” costs of plant and depreciation) that might be allocated to the end products or services. Some large insurers have tried to overcome the lack of connection between resources used and health care services provided. Medicare has developed “approximate” payment methodologies that “bundle” unaccounted-for costs into a set of payment categories from which health care providers are paid (e.g., DRGs – Diagnosis Related Groups and managed care reimbursement formulas such as per diems). Managed care plans have relied on the experience-rated data on an insured pool’s consumption of health care services as the basis for determining “cost-based” monthly premiums. The net result for most health care systems is that cost-related data from many health care accounting systems, such as billing charges and insurance claims, do not reflect the component costs of resources used in providing health care services.

The paucity of established accounting methodology to link raw materials and resources to the provision of health care services severely challenges development of health care service units to use as building blocks for calculating costs of care. The level of specificity for service units varies by program. For example, “hospice” represents a heterogeneous basket of different service units, and the level of detail in identifying service units within the “hospice” line item often varies in accordance with the perspective of the researchers and goals of the study. This is inevitable and appropriate. However, it is essential to clearly define the “units” and explain the advantages and limitations as appropriate. For example, in some studies it will be sufficient to quantify days of hospice care as a relevant cost unit. For others, components of hospice services, such as the number of visits and time spent by hospice nurse, social worker, physician and chaplain, will be required. Tabulating the “costs” of a service will depend on what the research questions are, what sources of data are available and the capacity of the research plan and budget.
Recommendations

- **Service units encompassed within cost analysis of palliative and end-of-life care programs must include the following:** inpatient hospital days; intensive care unit days; all physician (and dental) visits; emergency room visits; and outpatient visits. Other service units may include lab tests, behavioral health counselors and therapy visits, home care visits, medications and equipment. The bundling of component costs into categories such as “hospital days” or other service units may be a necessary compromise in some studies.

- To the extent possible, the detail of the program description should be matched with the scope and specificity of data within the cost accounting plan.

- Begin cost estimating with the identification and enumeration of the units of health care services provided in palliative and end-of-life care (or, alternately, during “the last year of life”).

- Avoid double counting and zero counting. These cautions arise because data on service units used may come from Medicare data files, commercial claims files, Medicaid claims files, recording by clinicians in medical records, administrative data, health care utilization surveys of patients, or some combination of sources. The risk of double counting is high when multiple, redundant bills are generated or multiple carriers are involved. Zero counting is a risk for non-reimbursed services.

Assign monetary values to health care service units.

Cost measures constructed from a service unit level have potential for avoiding many of the distortions and problems associated with idiosyncratic institutional-based cost accounting systems. The service unit approach requires a value standard for conversion of service units into dollar costs. Prices of health care service units that incorporate costs of component materials and resources, as well as the “opportunity costs” of those units provided would be ideal. Unfortunately, health care services are not provided through well-organized, competitive markets where supply and demand set per unit prices and enable opportunity costs to be accurately determined.

In addition to the previously noted problems of defining final services and output, health care is not a typical economic “good” or “service,” to which value can be assigned by market forces. Consumers usually do not have a “choice” in whether they become sick and need health care services. They usually rely on experts and the information or recommendations of providers in choosing their health care “needs.” As a result, market prices are not readily available or meaningful for valuing health care service units.

What are readily available are health care provider costs and revenue data, although they are not good measures of value. Value measures based on dollar values of billed charges, health plan and health insurance claims data and other administrative data sources include a number of non-service elements that make poor proxies for converting service units into costs. Cost-shifting between patient groups based on third party payer rates, institutional variation in price markups and profits, and inclusion of non-revenue cost centers and bad debt in many accounting systems obscure the specific economic costs of care. These factors apply whether one looks retrospectively at the costs during the last year of life or, prospectively, at the costs of palliative care for patients with limited life expectancy. Accounting data include non-resource charges and are sometimes available at considerable lag after the consumption of health care.

The monetary value (price/cost) of service units should be determined. Monetary values or costs per unit of service units may come from Medicare or other government payers, commercial payers, surveys of providers, surveys of employers or employees (wages), queries of patients, published studies and some combination of methods. The objective is to assign monetary values to all resources and materials used that reflect their opportunity costs from the cost perspective identified.

For example, a cost study from a public health
perspective might use the Medicare reimbursement system, which was designed to approximate the cost base for health care services as determined by local area wage and price levels, historical utilization and institutional status (e.g., teaching versus community hospital) as the common and acceptable set of cost formulas. A cost perspective of private health insurers would require price and economic cost data from private sector health plans as well as actuarial statistics for some population of health care consumers.

Recommendation

• Assign values for health care service units that are derived from a database consistent with the cost perspective of the study. Medicare reimbursement rates for public-based programs and private health plan costs and prices for non-public, group insurance programs are two examples of assigning per unit costs from a third party payer perspective.

Calculate cost per unit and total costs of end-of-life care.

Costs of care for each patient or group of patients should be determined by multiplying the total units of a particular service utilized by its monetary value to generate a per-unit cost and summing costs for all units of service utilized.

The use of health care service units as basic building blocks for cost accounting form a major component of the Workgroup’s recommended standards and guidelines. An accurate cost per unit of services would allow comparisons of palliative and end-of-life care services between individuals with different demographic characteristics (e.g., children versus the elderly), programmatic models (hospice versus home health) and over different time periods (five years ago versus two years ago).

A cost accounting template is included as Appendix B that captures the major medical services involved with palliative and end-of-life care programs. As presented by the Workgroup, the template indicates the details being collected at individual sites. For purposes of this report, the columns have been modified to indicate resources that might be captured at three levels of detail—simple counts, adjusted counts and billing units.

Recommendations

• Calculate the number of service units used by each patient at the most detailed level applicable as applicable to the goals of the study.
• Determine the costs of care for each patient or group of patients by multiplying the total units of a particular service utilized by a per-unit cost. Summing costs for all units of service utilized yields total costs.

SUMMARY AND CONCLUSIONS

Cost analyses for palliative and end-of-life health care programs represent only one dimension of program evaluation conducted to inform leaders in health care systems, locally and nationally, and policy-makers in making difficult decisions. Access to care and quality of care are also factors. It is typical to hope that there will be a negative relation between total costs and quality—that doing a better job by spending more in one area will result in lower total costs. While this holds for immunizations and selected preventive health services, it has infrequently been true for curative health services. Higher quality care typically costs more, although spending more doesn’t always ensure higher quality.

Some organizations are reluctant to engage in cost evaluations that could be misinterpreted as a move to reduce or withhold services. Several large health systems are expanding palliative and end-of-life interventions “on faith,” because they have determined it is the “right thing to do,” without hypothesizing or examining differences between program participants and non-participants in resource utilization, survival or costs. Other organizations may wish to examine the costs of palliative and end-of-life care programs only in relation to effects on the measurable impact on quality of patient care. Such analyses seek to determine the cost-effectiveness of specialized care programs and interventions, ideally comparing not
only their costs but also the outcomes of care for patients who are and are not enrolled in the program.

If the program under study is already included as a funded benefit, some stakeholders may use cost information to argue for an expansion in coverage or increases in insurance pricing, reimbursement or per member per month capitated payments. Others may use the same information to justify cost reductions. In this regard, some hospice executives worry that the Centers for Medicare and Medicaid Services (CMS) requirement for hospice cost data could be the first step toward reducing reimbursement under the Medicare Hospice Benefit. As these examples illustrate, stakeholders in cost analysis may have competing interests.

It is possible that increased spending on palliative and end-of-life care through a well-designed program may be associated with higher quality care and lowered total costs—a positive return on investment—over some range of time and program expense. If so, there also may well be a point of diminishing returns beyond which more service is associated with higher costs, with or without higher quality. These possibilities warrant careful study.

It is the Cost Accounting Peer Workgroup’s expectation that this set of recommendations will be a step toward better assessment of the costs and cost-effectiveness of programs to improve care, comfort and quality of life for seriously ill or injured patients and their families. In striving locally and nationally to make responsible decisions in allocation of limited resources, it is essential to understand the interplay of access, quality and costs. Sound and consistent accounting practices are critical to advancing improvements in care through the end of life.

Evaluation of current cost accounting methods and subsequent recommendations for practice should take the following four factors into consideration:

- The time needed to conduct rigorous analyses with the time frame for decision making;
- The budget and resources available to analysts for conducting a comprehensive cost analysis;
- The recognition that costs are only one health service delivery outcome, and that the context of the study and the impact on access to services and quality of care must always be considered; and
- The realization that costs are only one factor that drives health system and public policy decision making; however, the consideration of costs is essential to responsible health service delivery.
End Notes


Appendix A

OVERVIEW OF COST ACCOUNTING METHODS

Resource Costing Methods

The most common method of costing in evaluative studies is termed “the resource costing approach.” This approach involves collecting service units – typically at one institution, with all the institutional biases of how services are measured, and applying institution-specific costs (typically government payments) to the service units. A common criticism of the “resource costing approach” is its failure to capture units of medical care services in consistent and meaningful ways. 1

Price Adjustment Methods

An alternative to resource costing is “the price adjustment approach.” This method compares the monetary estimates of resources used, after adjustment for price level differences between countries, and over time, to standard current values. In order to attempt pooling of cost estimates, analysts must at least be certain as to which “secondary” cost estimates represent opportunity costs, charges or average costs. 2

In the U.S., the “price adjustment approach” underlies the use of Medicare Cost-to-Charge Ratios (CCR). Costs are estimated using the CCR approach by multiplying the number of units of each procedure billed by its Medicare charge and CCR and then summing these costs. Some health care organizations have begun to invest in sophisticated cost-accounting systems (CAS) that are capable of providing procedure-specific cost estimates, usually based on relative value units; these systems often rely on billing data to obtain service units.

A few studies have used a combination of Medicare CCR and CAS methods to estimate costs. 3, 4 In these studies, the CAS was for hospital costs only, with Medicare reimbursement (rather than institution costs), being used for professional services by using relative value units and a conversion factor from the Medicare Fee Schedule.

To overcome the issues of inaccurately (or non-transparently) measuring resource units, it is becoming more common in clinical trials to develop case report forms to capture all study end points, including medical service use. These studies then translate medical service use into costs using standard charges or costs, or a series of representative data sets of cost, to charge ratios by medical service category.

For analyses with specific objectives, much less intensive measures might be employed. For example, one study only involved the differential cost of medical devices, and therefore only captured the cost of the device. 5 A number of investigations in the end-of-life arena have approached accounting from a hospital perspective, focusing on incremental hospital days/costs, and therefore only capture these data. 6, 7, 8, 9

No cost accounting study is perfect or can capture all direct costs and indirect economic impacts of illness and care. Studies of only one medical resource/cost item are often criticized – suggesting that the use of focused studies may not be well received. In fact, even studies that capture the total costs of medical care services are criticized for not capturing the indirect costs. For example, family expenses of end-of-life care are
“Filling-In” the data on the Service Unit Grid should start with program intervention resources, including days/hours of administrator time, training time, transportation services and other program inputs. Generalizing intervention resources can result in loss of important service units. Grid construction should start with internal identification or accounting of all services for the program under consideration.

The illustrative service grid on the following pages is broken into parts and starts with Inpatient Hospital (item 1) and goes through Community Services (item 13).

---

**End Notes**


### Health Care Service

<table>
<thead>
<tr>
<th>Health Care Service</th>
<th>Simple Counts</th>
<th>Adjusted Counts</th>
<th>Billing Units</th>
</tr>
</thead>
</table>
| **1. Inpatient Hospital** | • Hospital admission  
• Hospital days | • Hospitalization by diagnosis and/or major service  
• ICU/CCU/Room day + length of stay | • Hospitalization (all days – adjusted for diagnosis = DRG) + length of stay  
• ICU/CCU/Room day + length of stay  
• Rehabilitation Unit + length of stay  
• ICD-9 procedures |
| | Medicare 2001 payments for “typical” end-of-life hospitalizations averaged $6,829 for 5.9 days, or $1,154 per day.  
Medicare payments are about half to two-thirds as much as commercial payments.  
With cost-to-charge ratios for hospitals averaging 50%, Medicare Payment may proxy institutional cost as well as payer cost.  
Payments are made for:  
Initial hospital care (mid-level of intensity) 99222 - $114.01  
Subsequent hospital care 99232 - $56.24  
and hospital discharge day 99238 - $67.72.  
Thus a three-day admission would cost at least $238. | Levinsky et al. provide resource use (% using) for ICU, Catheterization Dialysis, Ventilator, Pulmonary artery monitor -but not cost of each (payments are by DRG)  
Use of ICU and procedures all add to physician cost. Many diagnoses (especially surgical diagnosis) have implied physician services. | |
| **2. Outpatient** | • Visits + services  
• Pharmacy  
• Injectibles  
• Chemo  
• Home infusion  
• Imaging | • Visits by type of service received + services | • Visits by ambulatory visit groups AVG / ambulatory patient classification APC + services |
| | “Outpatient” covers many services – some similar to physician office visits, some like hospitalizations. | Examples: radiation single area (300) = $99.48  
radiation 3 or more areas (302) = $412.47. | APCs (Average Per Capita Costs) include a National Payment Rate (local area wage adjusted) and a Coinsurance rate (averaging 20%). For APCs, the 2001 minimum is $0 and maximum is $14,250. |
<table>
<thead>
<tr>
<th>Health Care Service</th>
<th>Simple Counts</th>
<th>Adjusted Counts</th>
<th>Billing Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Emergency Room</td>
<td>• Visits</td>
<td>• Visits by type of service</td>
<td>• Visits by relative value units — RBRVs/ RVUs (physician) and/or APC (facility)</td>
</tr>
<tr>
<td></td>
<td>Emergency room visits, like outpatient care, cover a variety of services.</td>
<td>Including additional procedures lends greater clarity on resource use.</td>
<td>RVUs: Medicare/Average 99282 M=$27.93 A=$66 99283 M=$62.74 A=$138 99284 M=$97.94 A=$215</td>
</tr>
<tr>
<td></td>
<td>The distribution of ER visits may differ for palliative and end-of-life care, but the overall average is for mid-level visits, for which the total Medicare payment is $168.75.</td>
<td></td>
<td>APCs: $610 Low Level $67.32  611 Mid Level $106.01  612 High Level $160.27</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>+ additional services, procedures</td>
</tr>
<tr>
<td>4. Physician²</td>
<td>• Visit to physician</td>
<td>• Visits to primary care physicians (evaluation and management)</td>
<td>• Visits by CPT-4 or service codes</td>
</tr>
<tr>
<td></td>
<td>Routine Office Visits are generally paid by duration of visit</td>
<td>• Visits to specialists (by specialty)</td>
<td>Note that payment amounts are total, and include the patient-paid portion, the deductible, which is $100 (Per Year) for Medicare in 2001 and coinsurance, which is 20%.</td>
</tr>
<tr>
<td></td>
<td>Level 1  &lt;15, $21</td>
<td>• Visits to clinics</td>
<td>Primary care physician fees are similar among Medicare and private insurance. Private insurance fees for specialist procedures average double Medicare rates. Medicaid averages 65% of Medicare rates.</td>
</tr>
<tr>
<td></td>
<td>Level 2  15-29, $37.49</td>
<td>• Telephonic consultations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Level 3  30-44, $52.41</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Level 4  46-60, $82.64</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Level 5  60+, $120.90</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The majority of visits (1 hospice study) are level 3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Among Medicare and fee surveys, $50 is common.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Care Service</td>
<td>Simple Counts</td>
<td>Adjusted Counts</td>
<td>Billing Units</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>---------------</td>
<td>-----------------</td>
<td>---------------</td>
</tr>
<tr>
<td>5. Laboratory Tests</td>
<td>• Number of tests Counting the number of tests can be difficult, as institutional “shorthand” is often used. One unpublished hospice study used $25 as an average cost/test.</td>
<td>• Number of tests by type and location</td>
<td>• Tests by CPT-4 (physician) and/or APC (outpatient) • Included for inpatient care</td>
</tr>
<tr>
<td><strong>Medications may be delivered in hospital (included in most prices), provided to patients on an outpatient basis or provided to patients during treatment (IV).</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Drugs</td>
<td>• Number of prescriptions (separate from Cancer chemotherapy and other services) For medications provided during treatment, there may also be a provider payment.</td>
<td>• Number of prescriptions by type / medication / dose / time</td>
<td>• Drugs by uniform code</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Therapy and Counseling</td>
<td>• Counseling visits</td>
<td>• Visits by provider type (social worker, chaplain, volunteer, physician, physical therapist, occupational therapist, dietitian, other therapist) • Caregiver after-hour call • Volunteer hours</td>
<td>• Visits and length (hours, minutes) by provider type and CPT-4 (if applicable)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Nursing Home</td>
<td>• Admission and length of stay For SNF (skilled nursing facility) care, Medicare average rates for 2001: Urban: $295/day Rural: $304/day</td>
<td>• Admission and length of stay by diagnosis and facility type (SNF, nursing home, etc.)</td>
<td>• Admission and length of stay by diagnosis and facility type (SNF, nursing home, etc.) • Days – adjusted for resource utilization groups (RUGs) or activities of daily living (ADLs) Adjustments for RUGs given on the SNF worksheet.</td>
</tr>
<tr>
<td>Health Care Service</td>
<td>Simple Counts</td>
<td>Adjusted Counts</td>
<td>Billing Units</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------</td>
<td>----------------</td>
<td>---------------</td>
</tr>
<tr>
<td>9. Home Care⁵</td>
<td>• Number of visits&lt;br&gt;&lt;br&gt;Total average per visit $43.54, which may include many services.</td>
<td>• Visits by provider type (skilled nurse, occupational therapist, respiratory therapist, etc.)&lt;br&gt;• And service</td>
<td>• Visits by provider type&lt;br&gt;• Days for respite and continuous and inpatient care and professional care</td>
</tr>
<tr>
<td>10. Hospice⁶</td>
<td>• Admission&lt;br&gt;• Number of visits</td>
<td>• Number of visits (duration of course of care) by type (home visit, spiritual visit, bereavement visit, volunteer visit, and hospice days)</td>
<td>• Visits by provider, treatment and time per visit</td>
</tr>
<tr>
<td>11. Medical Equipment</td>
<td>• Durable medical equipment (DME) by product class (respiratory, physical therapy, etc.)</td>
<td>• DME by product type&lt;br&gt;• Consumables</td>
<td>• DME by HCPCS Code&lt;br&gt;• Consumables</td>
</tr>
<tr>
<td>12. Paid/Unpaid Caregiving⁷</td>
<td>• Days of care</td>
<td>• Hours/day, days/week by provider type&lt;br&gt;• For family/friends, days/hours work lost; loss of job; loss of job benefits</td>
<td>• Days of paid care, by provider type&lt;br&gt;• For family/friends, days/hours work lost; loss of job; loss of job benefits</td>
</tr>
<tr>
<td>13. Community Services</td>
<td>• Number of services</td>
<td>• Services by type (counseling, day care, financial, legal, meal assistance, pastoral and transportation)</td>
<td>• n/a</td>
</tr>
</tbody>
</table>
1 Charge data over all DRGs (Diagnosis Related Groups) is a rough proxy for the cost of hospital days. Mean charge data can be divided by length of stay measured by number of days. An example of cost data based on Medicare, Medicaid and other types of charges for hospital stays is illustrated below with the data taken from HCUPnet, Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality, Rockville, MD (http://www.ahrq.gov/data/hcup/hcupnet.htm).

### Mean Charges and Length of Stay by Patient and Hospital Characteristics for All Discharges

<table>
<thead>
<tr>
<th></th>
<th>Total Number of Discharges</th>
<th>LOS, days (mean)</th>
<th>Charges, $ (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>U.S. Total</strong></td>
<td>35,406,187 (100.0%)</td>
<td>4.9</td>
<td>11,294</td>
</tr>
<tr>
<td><strong>By Payer</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>12,246,563 (34.6%)</td>
<td>6.3</td>
<td>14,524</td>
</tr>
<tr>
<td>Medicaid</td>
<td>6,977,169 (19.7%)</td>
<td>4.9</td>
<td>9,466</td>
</tr>
<tr>
<td>Commercial</td>
<td>13,199,769 (37.3%)</td>
<td>3.7</td>
<td>9,542</td>
</tr>
<tr>
<td>Uninsured</td>
<td>1,683,725 (4.8%)</td>
<td>3.9</td>
<td>8,756</td>
</tr>
<tr>
<td>Other</td>
<td>1,220,183 (3.4%)</td>
<td>4.4</td>
<td>11,639</td>
</tr>
<tr>
<td>Missing</td>
<td>78,778 (0.2%)</td>
<td>5.8</td>
<td>11,842</td>
</tr>
<tr>
<td><strong>By Region</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>7,424,394 (21.0%)</td>
<td>5.7</td>
<td>11,611</td>
</tr>
<tr>
<td>Midwest</td>
<td>8,331,919 (23.5%)</td>
<td>4.8</td>
<td>10,281</td>
</tr>
<tr>
<td>South</td>
<td>13,098,407 (37.0%)</td>
<td>4.8</td>
<td>10,740</td>
</tr>
<tr>
<td>West</td>
<td>6,551,467 (18.5%)</td>
<td>4.2</td>
<td>13,386</td>
</tr>
<tr>
<td><strong>By State</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arizona 1999</td>
<td>560,237</td>
<td>3.9</td>
<td>13,979</td>
</tr>
<tr>
<td>Iowa 1999</td>
<td>353,393</td>
<td>4.5</td>
<td>8,703</td>
</tr>
</tbody>
</table>

Patients admitted to an intensive care unit present additional issues of costing. The database: data used in the 100 Top Hospitals: ICU Benchmarks for Success study are from Solucient’s DRG and hospital databases for 1998 and 1999, the two most recent years available.

Data used to calculate the clinical measures for this study are from the DRG database. This database is based on the publicly available MedPAR (Medicare Provider Analysis and Review) data set from the Health Care Financing Administration. Data from Solucient’s hospital database are also used to calculate hospital-specific cost-to-charge ratios that are applied to ICU-related ancillary revenue center charges. The primary source of these data is the Medicare costs report, which is filed annually by every U.S. hospital that participates in the Medicare program.

The patient population is stratified into three groups that cover both a range of ICU-related procedures and diagnoses and capture different clinical pathways through which a patient enters an ICU:

1. Patients who present with medical diagnoses, such as stroke or pneumonia (“Admission Diagnosis Group”)
2. Patients who enter an ICU after surgery (“Primary Procedure Group”)
3. Patients on a mechanical ventilator for at least four days (“Mechanical Ventilation Group”)

These are the most critically ill patients in the study.
An example of cost per ICU day for the Admission Diagnosis Group is shown below:

![Adjusted ICU-Related Ancillary Cost per ICU Day for Admission Diagnosis Group](image)

Source: http://www.100tophospitals.com/Studies/icu00/methodology.htm.

2 Percentage of Total Responses by Agreement with Experts:

<table>
<thead>
<tr>
<th>Case</th>
<th>Undercode %</th>
<th>In Agreement %</th>
<th>Overcode %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Established patients</td>
<td>32.7*</td>
<td>51.6*</td>
<td>15.6*</td>
</tr>
<tr>
<td>New patients</td>
<td>1.1*</td>
<td>17.3*</td>
<td>81.5*</td>
</tr>
</tbody>
</table>

*P < .001.


3 Physician offices and hospitals are reimbursed for drugs and biologicals based on 95 percent of the AWP (Average Wholesale Price).

<table>
<thead>
<tr>
<th>Chemotherapy – Professional</th>
<th>Code</th>
<th>Medicare</th>
</tr>
</thead>
<tbody>
<tr>
<td>IV infusion</td>
<td>90780</td>
<td>$44.38</td>
</tr>
<tr>
<td>IV injection SQ</td>
<td>90782</td>
<td>$4.59</td>
</tr>
<tr>
<td>IV injection</td>
<td>90784</td>
<td>$19.13</td>
</tr>
<tr>
<td>Pulse Oximetry</td>
<td>94760</td>
<td>$4.21</td>
</tr>
<tr>
<td>Chemo, sub cut/IM</td>
<td>96400</td>
<td>$5.36</td>
</tr>
<tr>
<td>Chemo, push technique</td>
<td>96408</td>
<td>$38.64</td>
</tr>
<tr>
<td>Chemo, infusion</td>
<td>96410</td>
<td>$61.60</td>
</tr>
<tr>
<td>Chemo, infusion add-on</td>
<td>96420</td>
<td>$50.12</td>
</tr>
<tr>
<td>Chemo, intra arterial, push tech.</td>
<td>96420</td>
<td>$50.12</td>
</tr>
<tr>
<td>Intra arterial infusion</td>
<td>96422</td>
<td>$49.35</td>
</tr>
<tr>
<td>Intra arterial infusion w/pump</td>
<td>96425</td>
<td>$57.00</td>
</tr>
<tr>
<td>Chemo into CNS</td>
<td>96450</td>
<td>$109.04</td>
</tr>
<tr>
<td>Pump refill, mant. (portable)</td>
<td>96520</td>
<td>$35.58</td>
</tr>
<tr>
<td>Pump refill, mant. (implant.)</td>
<td>96530</td>
<td>$42.47</td>
</tr>
<tr>
<td>Chemo injection</td>
<td>96542</td>
<td>$78.05</td>
</tr>
</tbody>
</table>
Illustration: Six months (1/2) of one patient’s recorded use.

<table>
<thead>
<tr>
<th>MED</th>
<th>Dose</th>
<th>Route</th>
<th>Start</th>
<th>End</th>
<th>Price</th>
</tr>
</thead>
<tbody>
<tr>
<td>Axid</td>
<td>150mg BID</td>
<td>po</td>
<td>3/15/99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>theophylline</td>
<td>200mg TID</td>
<td>po</td>
<td>3/15/99</td>
<td>2/10/00</td>
<td></td>
</tr>
<tr>
<td>potassium Cl</td>
<td>10meq TID</td>
<td>po</td>
<td>3/15/99</td>
<td>2/10/00</td>
<td></td>
</tr>
<tr>
<td>Micronase</td>
<td>5mg qd</td>
<td>po</td>
<td>3/15/99</td>
<td>2/10/00</td>
<td></td>
</tr>
<tr>
<td>Aldactone</td>
<td>25mg BID</td>
<td>po</td>
<td>3/15/99</td>
<td>2/10/00</td>
<td></td>
</tr>
<tr>
<td>Darvocet N-100</td>
<td>1-2 q4hrs prn</td>
<td>po</td>
<td>3/15/99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ativan</td>
<td>0.5mg QID prn</td>
<td>po</td>
<td>4/12/99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>quinine sulfate</td>
<td>260-520mg qhs</td>
<td>po</td>
<td>4/20/99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elavil</td>
<td>50mg qhs</td>
<td>po</td>
<td>5/27/99</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zofran</td>
<td>8mg q8hr x 5d with chemo</td>
<td>po</td>
<td>6/21/99</td>
<td>9/30/99</td>
<td></td>
</tr>
<tr>
<td>Cytoxan</td>
<td>885mg q21-28d</td>
<td>IVPB</td>
<td>7/1/99</td>
<td>9/30/99</td>
<td>?</td>
</tr>
<tr>
<td>Adriamycin</td>
<td>71mg q21-28d</td>
<td>IVPB</td>
<td>7/1/99</td>
<td>9/30/99</td>
<td></td>
</tr>
<tr>
<td>5FU</td>
<td>885mg q21-28d</td>
<td>IVPB</td>
<td>7/1/99</td>
<td>9/30/99</td>
<td></td>
</tr>
<tr>
<td>Kytril</td>
<td>1mg ac chemo</td>
<td>IVPB</td>
<td>7/1/99</td>
<td>9/30/99</td>
<td></td>
</tr>
<tr>
<td>naproxen</td>
<td>375mg BID</td>
<td>po</td>
<td>7/15/99</td>
<td>8/15/99</td>
<td>?</td>
</tr>
<tr>
<td>Cipro</td>
<td>500mg BID x 7d</td>
<td>po</td>
<td>7/18/99</td>
<td>7/25/99</td>
<td></td>
</tr>
</tbody>
</table>

Cytoxan (cyclophosphamid...): 25mg (30 tablet)
Cytoxan (cyclophosphamid...): 25mg (60 tablet)
Cytoxan (cyclophosphamid...): 25mg (90 tablet)
Cytoxan (cyclophosphamid...): 25mg (100 tablet)
Cytoxan: 2gm (6 sdv)
Cytoxan: 500mg (12 sdv) *
Cytoxan (cyclophosphamid...): 50mg (30 tablet)
Cytoxan (cyclophosphamid...): 50mg (60 tablet)
Cytoxan (cyclophosphamid...): 50mg (90 tablet)
Cytoxan (cyclophosphamid...): 50mg (100 tablet)

* RxUSA.com (12) $240.
1 week mo, 6 months = 3 units = $720.

A typical dose of Imuran or Cytoxan is 125 to 150 milligrams (mg) a day given orally. A low dose is 75 mg or less. Cytoxan can be given at a much higher dose intravenously on a monthly basis. This may be quite effective for severe kidney disease and may help to avoid some of the side effects that occur with daily oral dosages of this drug (http://www.destinationrx.com/prescriptions/).

Anaprox (naproxen) 275mg (30 tablet)
Anaprox (naproxen) 275mg (60 tablet)
Anaprox (naproxen) 275mg (90 tablet)
Anaprox (naproxen) 275mg (100 tablet)
Anaprox DS (naproxen) 550mg (30 tablet)
Anaprox DS (naproxen) 550mg (90 tablet)
Anaprox DS (naproxen) 550mg (100 tablet)
Naprosyn (naproxen) 125mg/5ml (300 suspension)
Naprosyn (naproxen) 125mg/5ml (480 suspension)
Naprosyn (naproxen) 250mg (30 tablet)
Naprosyn (naproxen) 375mg (30 tablet)

<table>
<thead>
<tr>
<th>Store</th>
<th>Generic</th>
<th>Brand</th>
</tr>
</thead>
<tbody>
<tr>
<td>AARP</td>
<td>$ 8.85</td>
<td>$36.40</td>
</tr>
<tr>
<td>Costco.com</td>
<td>n/a</td>
<td>$36.79</td>
</tr>
<tr>
<td>Eckerd.com</td>
<td>$12.55</td>
<td>$34.90</td>
</tr>
<tr>
<td>FamilyMeds.com</td>
<td>$ 9.87</td>
<td>$37.87</td>
</tr>
<tr>
<td>PrescriptionOnline</td>
<td>$ 6.00</td>
<td>$27.00</td>
</tr>
<tr>
<td>RxUSA.com</td>
<td>$ 9.95</td>
<td>n/a</td>
</tr>
<tr>
<td>VitalRx.com</td>
<td>n/a</td>
<td>$36.03</td>
</tr>
<tr>
<td>WebRx.com</td>
<td>$ 9.87</td>
<td>$37.87</td>
</tr>
</tbody>
</table>

4 Case Mix Adjustment: Per diem payments for each admission are case-mix adjusted using a resident classification system (Resource Utilization Groups III) based on data from resident assessments (MDS 2.0) and relative weights developed from staff time data.

Geographic Adjustment: The labor portion of the federal rates is adjusted for geographic variation in wages using the hospital wage index.
The following table illustrates some average cost and average number of visits data for 2001:

<table>
<thead>
<tr>
<th>HOME HEALTH DISCIPLINE TYPE</th>
<th>AVERAGE COST/VISIT</th>
<th>AVERAGE NUMBER</th>
<th>HOME HEALTH RATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Health Aide Services</td>
<td>$41.75</td>
<td>13.4</td>
<td>$559.45</td>
</tr>
<tr>
<td>Medical Social Services</td>
<td>$153.59</td>
<td>.32</td>
<td>$49.15</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>$104.76</td>
<td>.53</td>
<td>$55.52</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>$104.05</td>
<td>3.05</td>
<td>$317.55</td>
</tr>
<tr>
<td>Skilled Nursing</td>
<td>$94.96</td>
<td>14.08</td>
<td>$1,337.04</td>
</tr>
<tr>
<td>Speech Pathology</td>
<td>$113.26</td>
<td>.18</td>
<td>$20.39</td>
</tr>
<tr>
<td>Total Non-Standardized</td>
<td></td>
<td></td>
<td>$2,338.90</td>
</tr>
<tr>
<td>Average per Episode</td>
<td></td>
<td></td>
<td>$43.54</td>
</tr>
<tr>
<td>Total Non-Standardized per 60-Day (+ supplies)</td>
<td>$2,416.01</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medicare pays for hospice care on the basis of a set rate for each day of a beneficiary’s election of hospice. There are four different levels of payment that may be made, depending on the type of care being provided on given day:

<table>
<thead>
<tr>
<th>Type</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine home care day</td>
<td>$106.93</td>
</tr>
<tr>
<td>Continuous home care day</td>
<td>$624.13</td>
</tr>
<tr>
<td>Inpatient respite care day, each period is limited to five days</td>
<td>$110.62</td>
</tr>
<tr>
<td>General inpatient care</td>
<td>$475.69</td>
</tr>
</tbody>
</table>

The vast majority of hospice care days are paid at the routine home care rate. (All rates are subject to geographic adjustment.) “Inpatient care limitation,” the total number of inpatient days used by Medicare patients of a hospice in the aggregate may not exceed 20 percent of the total number of hospice days billed by a certified hospice in a given year.


In a series of studies by Emanuel and colleagues of incurably ill patients and their families, 34.7% had substantial care needs. Patients who had substantial care needs were more likely to report that they had a subjective sense of economic burden (44.9% compared with 35.3%); that 10% of their household income was spent on health care (28.0% compared with 17.0%); and that they or their families had to take out a loan or mortgage, spend their savings or obtain an additional job (16.3% compared with 10.2%).
Appendix C

Sample Resource Use Data Collection Form

The following data collection form represents a service unit form that reflects the service unit grid in practice, as used by a palliative care program at the University of Michigan.

<table>
<thead>
<tr>
<th>Routine Office Visit</th>
<th>Outpatient Visit</th>
<th>Lab Tests Performed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit type/length (min)</td>
<td>Visit type</td>
<td>Urinalysis</td>
</tr>
<tr>
<td>Level 1</td>
<td>1-15</td>
<td>99211 O</td>
</tr>
<tr>
<td>Level 2</td>
<td>15-20</td>
<td>99212 O</td>
</tr>
<tr>
<td>Level 3</td>
<td>30-44</td>
<td>99213 O</td>
</tr>
<tr>
<td>Other (describe)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chemotherapy – Professional</th>
<th>Chemotherapy – Outpatient</th>
<th>Chemotherapy agents (include Dose / Days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy, sc/in</td>
<td>99400 O</td>
<td>Chemo Except infuse</td>
</tr>
<tr>
<td>Inflammation chemotherapeutic ad</td>
<td>99402 O</td>
<td>Infusion Only</td>
</tr>
<tr>
<td>Chemo, push technique</td>
<td>99403 O</td>
<td>Chemo infusion + Other</td>
</tr>
<tr>
<td>Chemotherapy infusion method</td>
<td>99404 O</td>
<td>Infusion Except Chemo</td>
</tr>
<tr>
<td>Chemotherapy infusion technique</td>
<td>99405 O</td>
<td>Level 1 Tube changes</td>
</tr>
<tr>
<td>Chemotherapy infusion method</td>
<td>99406 O</td>
<td>Level II Tube changes</td>
</tr>
<tr>
<td>Chemotherapy infusion technique</td>
<td>99407 O</td>
<td>Rev Implant Infus Pump</td>
</tr>
<tr>
<td>Chemotherapy infusion technique</td>
<td>99408 O</td>
<td>Dxorubicin 10mg</td>
</tr>
<tr>
<td>Chemotherapy infusion technique</td>
<td>99409 O</td>
<td>Doxarubicin palmar fasciitis</td>
</tr>
<tr>
<td>Chemotherapy, iv/ios</td>
<td>99450 O</td>
<td>Transfusion</td>
</tr>
<tr>
<td>Pump refilling, maint</td>
<td>99520 O</td>
<td>Plasma</td>
</tr>
<tr>
<td>Chemotherapy infusion method</td>
<td>99542 O</td>
<td>Whole Blood</td>
</tr>
<tr>
<td>Chemo, unspecified</td>
<td>99543 O</td>
<td>Platelets</td>
</tr>
<tr>
<td>Chemo, unspecified</td>
<td>99544 O</td>
<td>Red Blood Cells</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non-Routine Office Visit</th>
<th>Emergency Room Visit</th>
<th>Non-Routine Visit/Emergency Diagnoses – Primary (1) Secondary (2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiology</td>
<td>99213 O</td>
<td>Low Level Emergency</td>
</tr>
<tr>
<td>Gastroenterology</td>
<td>99214 O</td>
<td>Mid Level Emergency</td>
</tr>
<tr>
<td>Hem/onc</td>
<td>99215 O</td>
<td>Hi Level Emergency</td>
</tr>
<tr>
<td>General Practice</td>
<td>99216 O</td>
<td>Convulsions</td>
</tr>
<tr>
<td>Ophthalmology</td>
<td>99217 O</td>
<td>Cough</td>
</tr>
<tr>
<td>Pulmonology</td>
<td>99218 O</td>
<td>Depression</td>
</tr>
<tr>
<td>Radiology</td>
<td>99219 O</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Urology</td>
<td>99220 O</td>
<td>Dyspepsia</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>99221 O</td>
<td>Fever</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnostic Services</th>
<th>Outpatient Treatments</th>
<th>Hospitalization (DRG)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone scan</td>
<td>282 O</td>
<td>PET Scan</td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>156 O</td>
<td>Pulmonary function</td>
</tr>
<tr>
<td>CT Scan</td>
<td>283 O</td>
<td>Sigmoidoscopy</td>
</tr>
<tr>
<td>Diptheria</td>
<td>269 O</td>
<td>Stress test</td>
</tr>
<tr>
<td>Echocardiogram</td>
<td>612 O</td>
<td>Ultrasound</td>
</tr>
<tr>
<td>ECG</td>
<td>99 O</td>
<td>Upper GI</td>
</tr>
<tr>
<td>Mammogram</td>
<td>271 O</td>
<td>X-ray chest</td>
</tr>
<tr>
<td>MRI</td>
<td>294 O</td>
<td>Other (specify)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Transportation</th>
<th>Home Care (number of visits)</th>
<th>Hospice Care – Not HOM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulance service, non-emergency, basic life support</td>
<td>A0600 O</td>
<td>Home Health Aide</td>
</tr>
<tr>
<td>Ambulance service, emergency, basic life support</td>
<td>A0602 O</td>
<td>Medical Social Services</td>
</tr>
<tr>
<td>Ambulance service, emergency, advanced life support</td>
<td>A0604 O</td>
<td>Occupational Therapy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Admission Date</th>
<th>Discharge Date</th>
<th>Discharge to: Home</th>
<th>SNF</th>
<th>Decreased O</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nervous system neoplasms</td>
<td>10 O</td>
<td>Cardiac arrhythmia</td>
<td>138 O</td>
<td>Kidney, ureter &amp; bladder procedures</td>
</tr>
<tr>
<td>Cerebrovascular, except TIA</td>
<td>14 O</td>
<td>Other Circulatory diagnosis</td>
<td>144 O</td>
<td>Renal failure</td>
</tr>
<tr>
<td>TIA &amp; cerebrovascular occlusion</td>
<td>15 O</td>
<td>GI obstruction</td>
<td>186 O</td>
<td>Renal failure</td>
</tr>
<tr>
<td>Respiratory infection</td>
<td>79 O</td>
<td>Fract &amp; onn tissue malignancy</td>
<td>239 O</td>
<td>Lymphoma &amp; non-acute leukemia</td>
</tr>
<tr>
<td>Simple pneumonia</td>
<td>88 O</td>
<td>Total mastectomy</td>
<td>257 O</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Cirrhosis liver &amp; renal failure</td>
<td>121 O</td>
<td>Malignant breast disorder</td>
<td>274 O</td>
<td>Other (specify)</td>
</tr>
<tr>
<td>Heart failure &amp; shock</td>
<td>127 O</td>
<td>Metabolic disorder</td>
<td>296 O</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skilled Nursing Facility</th>
<th>Nursing Home</th>
<th>Days</th>
<th>Hospice Care – Not HOM</th>
</tr>
</thead>
<tbody>
<tr>
<td>RUG III – category (if known)</td>
<td>Admit Date</td>
<td>Discharge</td>
<td>Routine Home Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Continuous Home Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Inpatient Hospice Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>General Inpatient Care</td>
</tr>
</tbody>
</table>
Appendix D

Additional Resources


Beckwith S. “San Antonio Event Addressed ‘Leverage Points’ for Care.” *Last Acts: Care and Caring at the End of Life*.


The Center to Advance Palliative Care (CAPC). [www.capcsm.org](http://www.capcsm.org).


Culler SD, Callahan CM and Wolinsky FD. “Predicting Hospital Costs Among Older Descendents Over Time.” Medical Care, 33(11): 1089-1105, 1995.


Perls TT and Wood ER. “Acute Care Costs of the Oldest Old: They Cost Less, Their Care Intensity is Less, and They go to Nonteaching Hospitals.” *Archives of Internal Medicine*, 156(7): 754-760, 1996.


The RAND Center to Improve Care of the Dying. [www.medicaring.org](http://www.medicaring.org).


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