

PALLIATIVE CARE: AN OPPORTUNITY FOR MEDICARE

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FOREWORD

This project was supported by The Robert Wood Johnson Foundation through the Center to Advance Palliative Care at the Mount Sinai School of Medicine. The authors wish to express their appreciation to both organizations and to all of the medical experts who provided their views on the current state of palliative care in Medicare and who reviewed this document in draft. While we have made every effort to accurately reflect the concerns of those we talked with, the views and recommendations expressed here are solely those of the authors.

Our study deals with those areas of regulatory and administrative activity within the Centers for Medicare and Medicaid Services (CMS) that could be changed in ways that would improve the delivery of palliative care services. In some instances, we suggest changes within CMS to enhance the understanding and acceptance of palliative care by both professionals and the general public. In others, we have identified areas where current regulatory and administrative practices are barriers to good palliative care and have suggested means for removing those barriers.

We should note that three very important topics are not covered here. The first is the hospice benefit under Medicare that, as a distinct legislative and regulatory entity, differs significantly from more general issues of palliative care. We hope to discuss the Medicare hospice benefit further in future reports in this series. The second is the question of hospital support for the establishment of palliative care centers. This topic, which is not exclusively a Medicare issue, is covered by several of the case studies in “Pioneer Programs in Palliative Care: Nine Case Studies,” which was published jointly by The Robert Wood Johnson Foundation and the Milbank Memorial Fund in 2000. The third is the many gaps in Medicare benefits, beginning with the lack of an outpatient drug benefit, which present serious problems to palliative care patients as they do to others in the program. Although clearly important, our sense was that these issues are well covered elsewhere in the literature.

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INTRODUCTION

The Medicare program currently pays for the health care services provided to approximately 80 percent of all individuals who die in the United States.¹ The Centers for Medicare and Medicaid Services (CMS), the Federal agency that administers the Medicare program, is therefore in a unique position to ensure that high quality palliative care is made available to all who need it. Much of CMS’s opportunity lies in areas such as quality assurance and quality regulation. Our goals in this paper are to outline problems faced by palliative care professionals that could be ameliorated by action on the part of CMS and to suggest practical solutions. We have focused on solutions which could be implemented relatively easily and which are not costly. Such changes, if carried out effectively, can move both CMS and practitioners towards a much broader understanding of palliative care, which we hope will eventually inform decisions such as improvements in the benefit package.

Patients who are expected to die within six months are candidates for hospice, as defined by Medicare. The group of patients who could benefit from palliative care is broader, but not as precisely defined. In general, experts in the field focus on two overlapping groups of patients: the chronically sick with conditions such as heart or lung disease who are not expected to survive more than a few years, and the “actively dying,” whose anticipated life expectancy is measured in days or weeks.

Medicare currently pays for palliative care services per se only within the hospice benefit. In order for care to be reimbursed under this benefit, patients must acknowledge they have been informed of their life-limiting condition and consent to receive services directed toward the alleviation of suffering and support in life closure rather than those directed towards cure. In addition, in order to be eligible for the Medicare hospice benefit, patients must have a “prognosis” of six months or less. Over time, the regulations imposed on the hospice benefit have contributed to narrowed access to services and have made innovation within the average hospice program difficult.² A number of large-volume, not-for-profit hospices have now begun to define themselves as “Comprehensive Hospice Centers” that, in addition to providing traditional hospice care, provide palliative services to patients who are not eligible for or do not choose to participate in the Medicare hospice benefit. They also conduct research and participate in teaching.

The hospice benefit statute and the regulations developed by CMS represented the best available model when hospices were introduced in this country over twenty-five years ago. They serve well those patients who have conditions for which disease-modifying therapy can be sharply distinguished from therapies with palliative intent. For others, however, the approach to palliative care has been altered by the fact that medical advances have blurred the bright line between treatment directed at the

SUMMARY OF PROBLEMS AND BARRIERS TO THE PRACTICE OF PALLIATIVE CARE

underlying disease and treatment directed at the relief of suffering. For many cancer patients, for example, treatments including radiation therapy, chemotherapy, blood transfusions and, when appropriate, surgery, can now be used to prolong the symptom-free period and enhance the quality of remaining life. While hospice care is still an appropriate choice for many individuals, good care at the end of life must allow for the full range of treatment choices and for the patient's and family's ability to participate in making those choices.*

It can be said that the principles of palliative care—such as the alleviation of pain and other physical symptoms and respect for the patient and family—are appropriate for all patients, not only those with chronic or fatal illnesses. Many experts we interviewed agree with this position, but still argue that patients who are either actively dying or facing likely death within the next few years are in particular need of improvements in their treatment. They also argue that better palliative care will inevitably lead to better care for all patients in the same ways that other specialties have, over time, influenced innovations in the practices of generalists.

Experts in the field draw a distinction between palliative medicine, which is restricted to the services provided by physicians and a limited range of other health professionals, and palliative care, which includes the broader array of services provided by the full interdisciplinary team. Since Medicare payments tend to be limited to palliative medicine, and since we have not discussed expansion in the benefit package, many of our suggestions are aimed only at palliative medicine. Wherever possible, however, within the context we have chosen, we also address the broader field of palliative care.

This report reflects both our review of the palliative care literature and interviews with medical palliative care experts. The choice of topics and barriers is the authors' responsibility, and again, these are within the framework of Medicare and palliative medicine. We interviewed professionals who are experts in the field of palliative care and asked them to identify problem areas in the delivery of palliative services, as well as success stories in improving the quality of palliative care within their institutions.

Our interviews were largely limited to physicians and to individuals already well-defined with the palliative care and hospice movements. While we fully appreciate the multi-disciplinary nature of palliative services, the limited scope of this project did not provide an opportunity to work with very many of the other important members of the palliative care team, such as nurses and social workers. In addition, the perspectives of generalist physicians who deal only intermittently with palliative services are not reflected here.

*Those not familiar with this change are encouraged to read the collected writings of John Diamond, a British weekly columnist who chronicled his treatments and his life during the four years between his diagnosis with oropharyngeal cancer and his death in early 2001. He was well aware of and articulate about his life expectancy. He received intermittent active treatment up until the time of his death and managed, as a result, to travel with his family, buy a motorcycle and a gold Cadillac, learn to drink champagne through a g-tube, and in general enjoy himself to the fullest. A number of his most recent columns are available at www.thetimes.co.uk/johndiamond/

LACK OF KNOWLEDGE AND UNDERSTANDING: MANY CLINICIANS DO NOT KNOW HOW TO PRACTICE GOOD PALLIATIVE MEDICINE.

The literature shows and the experts confirm that many clinicians do not practice good palliative care because they have not been adequately educated regarding end-of-life and palliative issues. Until recently, the concepts of palliative and end-of-life care were not addressed in medical schools or residency programs. The topic is still often not addressed in clinical textbooks and is rarely a part of quality improvement or continuing education at most medical centers.^{3,4,5,6,7}

Specifically, many clinicians are uncomfortable talking to their patients about the inability of contemporary medicine to achieve cure or remission of their condition. They do not know how to discuss the kinds of choices that patients and families want to address. Many in the medical community perceive death as a "failure." Research in the 1980s demonstrated that communication between physician and patient regarding end-of-life issues occurred mostly during crisis situations.^{8, 9,10} Similar conclusions can be taken from the SUPPORT study: "the SUPPORT patients were all seriously ill, and their dying proved to be predictable, yet discussions and decisions substantially in advance of death were uncommon."¹¹ This means that the full exploration of all aspects of advance care planning may not take place while the patient is well enough to participate.

In addition, many clinicians do not manage pain well. Despite the availability of approaches that provide comfort without significant side effects, much of the care of the seriously ill is still characterized by "...unrelieved pain, illogical prescribing of analgesics, and widespread "opiophobia."¹² In some jurisdictions in the United States, physicians are concerned that appropriate use of opioids will be viewed by the legal authorities as "over-prescribing" and could lead to investigation and even prosecution. One expert noted that there is wide variation across states in the use of opioids, a fact that has not been subject to evaluation and research.

Other aspects of palliative medicine that are not well managed by many clinicians include the management of other symptoms such as shortness of breath, anxiety, depression, nausea, and vomiting. In addition, physicians are rarely able to facilitate effective grieving and bereavement for both dying patients and their families, though it is recognized as an important component of the care process.

All of the limitations described for practicing clinicians can also be found in individuals in leadership positions in care delivery settings. Hospital, nursing home, managed care and other medical directors often have little or no knowledge of the principles of palliative care. The policies that they help to develop do not always ensure access for patients to palliative care. Knowledge of palliative care and commitment to its principles among medical leaders can make a

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significant difference. For example, the experts identified several managed care plans providing excellent palliative care, due in large part to the visionary leadership behind them.

MODIFY the Medicare Conditions of Participation for Hospitals, Nursing Homes and Home Health Agencies (and work with the Joint Commission on Accreditation of Health Care Organizations to modify their standards) in the following ways:

REQUIRE that hospitals and nursing homes create an environment in which palliative care is widely understood and practiced. These requirements should be developed in a manner consistent with other aspects of the Hospital Standards and the Conditions of Participation with emphasis on the desired outcome rather than on the means by which institutions achieve that outcome. Exposure to the standardized educational programs offered by the EPEC Project (Education for Physicians on End-of-Life Care) and the ELNEC Project (End-of-Life Nursing Education Consortium) should be either strongly encouraged or required.

ENSURE that the measures of hospital quality now being developed by the National Forum for Quality Measurement and Reporting are consistent with the quality measures recently developed by the National Hospice and Palliative Care Organization (NHPCO) for Medicare hospice use. Use of consistent measures across settings will help to enhance the understanding of good palliative care.

IDENTIFY AND DISSEMINATE best practices in the field, as part of the effort to improve hospital-based palliative care.

REQUIRE all Professional Review Organizations (PROs) to include at least one expert in palliative care on their boards. If no palliative care expert is available, at least one member of the PRO board should attend a palliative care training session offered by EPEC or ELNEC.

ADD an expert in palliative care to the CMS Practicing Physicians Advisory Council.

REQUIRE the appointment of palliative care experts to all Medicare carrier advisory committees or, if no suitable candidate is available, require at least one member of the carrier advisory committee to attend a palliative care training session offered by EPEC or ELNEC.

REVIEW all CMS advisory committees that include physicians and other health professionals to evaluate the appropriateness of including palliative care experts.

LACK OF CONTINUITY: THE LACK OF CONTINUITY IN OUR SYSTEM MEANS THAT PATIENT PREFERENCES, EVEN WHEN CAREFULLY DELINEATED, ARE OFTEN FORGOTTEN OR IGNORED AT THE TIME OF TRANSFER.

RECOMMENDATIONS:

INAPPROPRIATE DISCHARGE FROM HOSPITALS: SERIOUSLY ILL & DYING PATIENTS ARE OFTEN DISCHARGED FROM HOSPITALS AGAINST THE WISHES OF FAMILY AND CAREGIVERS.

As the SUPPORT¹³ study has shown, even well-documented preferences to avoid resuscitation are frequently ignored when a patient changes doctors by virtue of being admitted to a hospital, leaving a hospital for a nursing home, or making any other change in care settings. This is particularly frustrating for the primary physician—whether she is an ambulatory care doctor or a hospital-based specialist—when a complex plan has been worked out with and agreed to by the patient and family and that agreement is ignored by the next physician caring for the patient.

Ideally, all patients receiving palliative care should receive coordination and continuity of that care in a manner consistent with requirements in the Medicare Conditions of Participation for Hospice and current standards of practice for hospice programs.¹⁴ In practice, however, the techniques used within hospice, which include the availability of staff at all times as well as an updating process to ensure that all caregivers and volunteers are aware of the patient's current status, are usually not available to providers outside of the formal hospice benefit.

CMS SHOULD PROVIDE funds to PROs to undertake innovative quality assurance activities that focus on improvements in methods to ensure that all caregivers honor patient and family wishes. For example, techniques such as “smart cards” containing information on the responsible primary care physician and on the patient's wishes could be tried.

DRAWING on its hospice experience, CMS should focus on innovative research to identify, develop, and promulgate best practices to enhance continuity for all patients.

THE DEVELOPMENT OF GOOD MODELS of continuity should be a focus of the research agenda developed by AHRQ and other appropriate agencies.

The DRG system provides an incentive to hospitals to discharge patients as quickly as possible; the payment system does not prescribe when patients should leave or which patients should be discharged early. Many of the experts we interviewed reported being told by their Utilization Review (UR) departments that “Medicare would not pay” for continued hospital service for a patient who has significant palliative care needs. This even extends to patients with a prognosis of hours to a few days. In the absence of a clear message to clinicians from CMS, and lacking extended training in the prospective payment system (PPS/DRG), physicians often capitulate to this pressure even though they may believe that an actively dying patient should not be asked to move for the last few days of life. One expert noted that the presence of a “do not resuscitate” (DNR) order was, in and of itself, considered by his

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hospital to be a signal that discharge should occur. Another noted that hospitals may find it economically more agreeable to provide hospice services rather than continued routine inpatient care to the patient whose length of stay exceeds the mean for a particular DRG.

A number of hospitals—particularly Catholic hospitals, such as Providence Health System in Oregon and St. Agnes Medical Center in Philadelphia—have instituted policies to ensure that their Utilization Review departments understand the need to provide care for those patients who are dying. These “compassionate non-discharge policies” apply to patients who no longer meet the usual acute level of care guidelines for hospitalization, whose death is imminent, and whose physician and family wish to have the patient remain in the hospital.

In addition to the recommendations for CMS policy listed below, practitioners should familiarize themselves with the principles of DRGs and work with their UR departments to develop appropriate policies for the actively dying patient. Dissemination of “best practices” by institutions that have implemented innovative policies in this area would also help.

ADD a section to the hospital accreditation manual describing optimal care of patients who are actively dying, clarifying the fact that CMS neither mandates nor encourages discharge for these individuals.

CMS SHOULD COMMUNICATE its position on hospital discharge of dying patients through an open letter to participating providers and through presentations to and meetings with specialty societies.

CMS SHOULD WORK WITH voluntary agencies and hospital associations to make patients, families and providers of palliative care aware of the patient’s rights under Medicare to appeal a discharge to the local PRO and to remain in the hospital while that review is being carried out.

CMS SHOULD ASK PROs to undertake a review of a sample of all patients who die within seven days of discharge from a hospital with the intention of defining and eliminating the causes of unwanted transfers, as well as identifying those situations in which transfer home was requested and deemed appropriate. Additional important palliative care topics could be covered in the same review, including the availability of in-home services for individuals not electing the hospice benefit and evaluation of communication with the patient and family regarding the grave nature of the patient’s condition.

CMS SHOULD ALSO ASK PROs to undertake a review of a sample of patients who die in a hospital to identify whether or not palliative care needs were met.

INAPPROPRIATE DISCHARGE FROM NURSING HOMES: A SIMILAR PROBLEM WITH A VERY DIFFERENT CAUSE EXISTS IN NURSING HOMES.

RECOMMENDATIONS:

A similar problem with a very different cause exists in nursing homes. Patients who are very close to death are often transferred to a hospital because of concern that an institutional death will “count against” the nursing home in its next inspection. While it is not possible to quantify the magnitude of this problem, all experts reported at least some experience with it. This practice can create unnecessary hardships and extreme distress for the patients and their families; it is one cause of the discontinuity in care decisions.

This problem is an unintended consequence of the major effort undertaken over the past twenty years to improve the care in our nation’s nursing homes. One important element of that improvement is the Minimum Data Set (MDS) that all nursing homes must collect and report on all Medicare and Medicaid patients. Information from the MDS has been used for some years now to identify nursing homes that appear not to be providing good care.

A major problem with the use of the MDS arises from the fact that State nursing home inspectors have not been trained to use the information in a way that adjusts for the patient’s underlying condition. Therefore, a home that delivers excellent palliative care, and as a result attracts a number of dying patients, will appear to have a “worse” death rate than one with no palliative care at all. CMS staff are well aware of this problem and have been working to develop more appropriate uses of the MDS; we encourage rapid implementation of the new approaches.

CMS SHOULD REVISE the use of MDS information to ensure that events such as deaths are judged against an appropriate denominator of patients, not against all patients.

CMS SHOULD MODIFY guidelines and training materials for State nursing home inspectors to reflect this improved use of the MDS.

CMS SHOULD DEVELOP AND PROMULGATE guidelines for the appropriate use of nursing home resources for patients who are actively dying.

OTHER TYPES OF INAPPROPRIATE CARE IN NURSING HOMES ARE DRIVEN BY REGULATION: MANY MEDICARE PATIENTS DIE IN NURSING HOMES RATHER THAN IN THE HOSPITAL OR AT HOME.

Many Medicare patients die in nursing homes rather than in the hospital or at home. This would seem to make nursing homes a logical place to develop palliative care and hospice services. There is now good evidence that hospice services provided in nursing homes benefit not only the enrolled patients but also other patients in the same institution as a result of improved understanding of the approach to palliative care on the part of all caregivers.¹⁵ At present, however, relatively few nursing homes provide their patients with access to palliative care.¹⁶

One reason there is not more palliative care in nursing homes is that the process of nursing home oversight often conflicts directly with good palliative care in a number of areas beyond unnecessary hospital transfers. Problems cited by experts include the fact that patients cared for in nursing homes may not receive appropriate psychoactive drugs and pain medications. Drugs such as major tranquilizers have been defined as risky for the average nursing home patient but are often very beneficial to the highly symptomatic dying patient. Many nursing homes, concerned about being cited for poor care on their next survey, put considerable pressure on physicians not to use the “forbidden” drugs even when there is a sound clinical reason to do so. Patients and their physicians also are often coerced by nursing homes into accepting intravenous hydration as well as some form of tube feeding. As one expert put it: “No one cares whether or not they are comfortable, so long as they die plump.” This results from the fact that rapid weight loss is another marker of poor care used by nursing home inspectors.

Here, too, an appropriate adjustment of the use of the MDS, with a more appropriate definition of the expected outcomes for patients whose plan of care is palliative, can do a great deal to relieve inappropriate pressure on clinicians. In addition, CMS can encourage the kind of links between nursing homes and hospices that are described in hospitals in a report prepared by CAPC and NHPCO.¹⁷

RECOMMENDATIONS:

MODIFY use of the MDS as already described.

FURTHER MODIFY guidelines and training materials for State nursing home inspectors as follows:

INCLUDE INFORMATION on best practices with respect to patients who are actively dying or whose plan of care is primarily for palliation.

ENSURE the right of patients and families to refuse tube feeding and hydration when desired.

DEFINE the appropriate use of the “forbidden” medications in treating patients for whom the plan of care is focused on palliation.

PROBLEMS WITH REIMBURSEMENT: INDIVIDUALS AND FAMILIES IN NEED OF PALLIATIVE CARE FACE A WIDE RANGE OF PROBLEMS IN REIMBURSEMENT.

DEVELOP AND PROMULGATE guidelines for the appropriate use of nursing home resources for patients who are actively dying.

EXPLORE the means by which more nursing homes could be encouraged to establish palliative care and hospice units or to cooperate more fully with existing providers of quality hospice care.

Individuals and families in need of palliative care face a wide range of problems in reimbursement. The most immediate and obvious is the lack of an outpatient drug benefit under Medicare, but many others can be listed. These include lack of respite and bereavement services as well as insufficient coverage of home health care to meet the needs of the patient receiving palliative care.

Most of these problems can be dealt with only through legislative change; some, such as the question of a drug benefit under Medicare, are already under active consideration. There are, however, steps that could be taken without great cost and, in most of the cases listed below, without new legislation. These changes could, if implemented, make a strong statement about CMS’s commitment to the importance of palliative care.

One particularly problematic reimbursement problem from the physician point of view arises from guidelines rather than law—that is, the regular denial of payment for palliative services delivered to hospitalized patients because of limits on what is known as “concurrent care.” Some years ago, faced with evidence of excessive use of consultations in some hospitals, CMS issued instructions to Medicare carriers to review carefully physician billings for hospitalized patients. “Concurrent care,” in the sense of regular daily visits from physicians other than the admitting physician, was held to be acceptable if the physicians were of different specialties but less likely to be appropriate when physicians are of the same specialty. Palliative care, lacking a formal training and certification process, is not considered a specialty. Since many palliative care experts are internists or family practitioners consulting to other internists or family practitioners, payment for these services is often denied.

One ironic effect of the rule is that physicians whose original training is in a field other than internal medicine/family practice do not experience difficulties. Palliative care experts whose background is neurology or anesthesia can deliver without difficulty the services that are denied when provided by internists and family practitioners.

Palliative care experts also express concern about the lack of adequate reimbursement for office visits for advanced care planning, although in this case the problem is low rates and difficulty with the rules about

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documentation and is common to all services which involve “evaluation and management.”

Finally, many experts noted that Medicare beneficiaries who have experienced the loss of a family member cannot receive counseling unless they are given a psychiatric diagnosis. The same is true for non-Medicare beneficiaries with private insurance.

MODIFY the Medicare carrier manual to acknowledge that concurrent care by two members of the same specialty is appropriate when the intention is palliative care.

DEVELOP a code for an extended visit in an office, in a hospital, or in a nursing home for planning end-of-life care (to be paid with appropriate limits on the frequency of use for any one patient).

INCLUDE bereavement counseling under the existing Medicare psychiatric benefit. This would enable current beneficiaries who have lost loved ones to be referred for such counseling without fear of either denial of services or a requirement that they be artificially labeled with a psychiatric diagnosis such as depression.

**LACK OF RESEARCH:
PALLIATIVE CARE EXPERTS’
SUGGESTIONS ON HOW
TO BETTER ORGANIZE
AND PAY FOR THE
DELIVERY OF GOOD
PALLIATIVE CARE.**

RECOMMENDATIONS:

The palliative care experts we interviewed offered a wide range of suggestions on how to better organize and pay for the delivery of good palliative care. Yet many of these ideas have not been tested or fully examined. Protocols for the appropriate use of palliative care in both hospitals and nursing homes are lacking. Information is also lacking regarding caregiver support. One expert noted that the caregiver literature is inconsistent and incomplete, and more research in this area is especially important because specific numbers are needed for the cost analysis of any legislation that may be proposed.

DEVELOP a research agenda specific to palliative care at CMS, at the Agency for Health Care Research and Quality (AHRQ), and at other Federal agencies as appropriate. This should include areas such as the development of practice guidelines and methods of quality improvement, as well as investigations into new approaches to reimbursement.

INCLUDE in the research agenda the development of demonstration projects related to the application of telemedicine and other forms of modern communication (such as the Internet) as case management tools to promote continuity of care across settings, and as a care tool in home care and skilled nursing facilities.

**LACK OF ATTENTION TO
PALLIATIVE CARE:
FOSTERING GREATER
UNDERSTANDING AND
BETTER PRACTICE.**

RECOMMENDATIONS:

We believe that CMS has a unique opportunity to foster greater understanding and better practice of palliative care. In order to do this, the agency must undertake a long-term transformation in collaboration with palliative care and hospice experts to ensure that all future policy is carefully considered with a view to its effect on the ability to relieve suffering and improve quality of life.

WE RECOMMEND that CMS undertake a comprehensive review of all agency policies that affect care at the end of life. This can be done either by agency personnel or by an outside organization. The review should include regulations, for both nursing homes and hospitals, quality assurance activities, reimbursement, research agendas, and communication with both the professional community and the general public. The goal should be to ensure that all policy is as consistent as possible with the principles of excellent palliative care.

PERSONS INTERVIEWED

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ENDNOTES

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