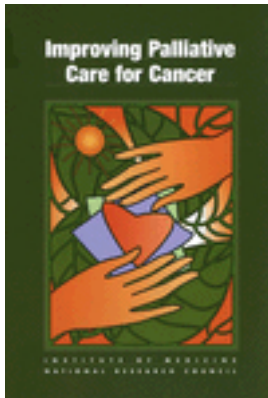


Free Executive Summary



Improving Palliative Care for Cancer

Kathleen M. Foley and Hellen Gelband, Editors,
National Cancer Policy Board, National Research
Council

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Improving Palliative Care for Cancer defines the major barriers that keep people from receiving excellent palliative care, as needed, throughout the course of their illness with cancer and recommends a series of steps forward.

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Part 1

Improving Palliative Care for Cancer

Kathleen M. Foley and Hellen Gelband, *Editors*

National Cancer Policy Board

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and

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its

release. The review of this report was overseen by Harold Sox of the Dartmouth-Hitchcock Medical Center, appointed by the NRC's Report Review Committee, who was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the National Cancer Policy Board, the Institute of Medicine, and the National Research Council.

Preface

It is innately human to comfort and provide care to those suffering from cancer, particularly those close to death. Yet what seems self-evident at an individual, personal level has, by and large, not guided policy at the level of institutions in this country. There is no argument that palliative care should be integrated into cancer care from diagnosis to death. But significant barriers—attitudinal, behavioral, economic, educational, and legal—still limit access to care for a large proportion of those dying from cancer, and in spite of tremendous scientific opportunities for medical progress against all the major symptoms associated with cancer and cancer death, public research institutions have not responded. In accepting a single-minded focus on research toward cure, we have inadvertently devalued the critical need to care for and support patients with advanced disease, and their families.

This report builds on and takes forward an agenda set out by the 1997 IOM report *Approaching Death: Improving Care at the End of Life*, which came at a time when leaders in palliative care and related fields had already begun to air issues surrounding care of the dying. That report identified significant gaps in knowledge about care at the end of life and the need for serious attention from biomedical, social science, and health services researchers. Most importantly, it recognized that the impediments to good care could be identified and potentially remedied. The report itself catalyzed further public involvement in specific initiatives—mostly pilot and demonstration projects and programs funded by the nonprofit foundation community, which are now coming to fruition.

There are no villains in this piece but ourselves and our culture. Public institutions and policymakers reflect dominant societal values that still deny dying and death. Although it does occur, change to improve care of the suffering and dying is slow and conflicted with the tension between cure and care. This report encourages continued innovation and collaboration of foundations and others, but focuses on ways in which the government can embrace opportunities to improve existing palliative care, make access to it equitable for all, and help realize better palliative interventions by making research funds more available.

It is a truism that death—not just our own—affects all of us, even if it is a topic most people do not want to contemplate for long. Death is inevitable, but severe suffering is not. Willpower and determination will be required, but it is time to move our public institutions toward policies that emphasize the importance of improving palliative care for those who want and need it. This report identifies the special needs of cancer patients and the importance of the clinical and research establishment involved in cancer care to take a leadership role in modeling the best quality care from diagnosis to death for all Americans.

Kathleen M. Foley, M.D.
Director, Project on Death in America, The Open Society

Acronyms and Abbreviations

AAMC	American Association of Medical Colleges
ACoS	American College of Surgeons
ACS	American Cancer Society
ADL	activities of daily living
AHRQ	Agency for Healthcare Research and Quality
AMA	American Medical Association
APA	American Psychiatric Association
APS	American Pain Society
ASCO	American Society of Clinical Oncology
ASPHO	American Society of Pediatric Hematology/Oncology
BFI	Brief Fatigue Inventory
CAHPS	Consumer Assessment of Health Plans Survey
CIS	Cancer Information Service
CME	continuing medical education
CNS	central nervous system
COPD	Chronic Obstructive Pulmonary Disease
CPR	Cardiopulmonary resuscitation
CPT	Current Procedural Terminology
DCTD	Division of Cancer Treatment and Diagnosis
DNR	do not resuscitate

DSM-IV	<i>Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition</i>
ECOG	Eastern Cooperative Oncology Group
HCFA	Health Care Financing Administration
HPCN	Harlem Palliative Care Network
HELP	Hospitalized Elderly Longitudinal Project
HRSA	Health Resources and Services Administration
ICD-9	International Classification of Diseases, 9 th revision
ICU	intensive care unit
IL-6	interleukin-6
INF- α	alpha-interferon
IOM	Institute of Medicine
IV	intravenous
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
LCME	Liaison Committee on Medical Education
MDS	Minimum Data Set
MedPAC	Medicare Payment Advisory Commission
MRI	magnetic resonance imaging
MSKCC	Memorial Sloan-Ketterin Cancer Center
NCCN	National Comprehensive Cancer Network
NCHS	National Center for Health Statistics
NCI	National Cancer Institute
NCPB	National Cancer Policy Board
NGH	North General Hospital
NHO	National Hospice Organization
NHPCO	National Hospice and Palliative Care Organization
NIA	National Institute on Aging
NIAID	National Institute of Allergy and Infectious Diseases
NIH	National Institutes of Health
NINR	National Institute of Nursing Research
NMFBS	National Mortality Followback Survey
OCD	obsessive-compulsive disorder
PCP	President's Cancer Panel

ACRONYMS AND ABBREVIATIONS

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PDIA	Project on Death in America
PDQ	Physician Data Query
PSDA	Patient Self-Determination Act
PTSD	post-traumatic stress disorder
PVS	persistent vegetative state
QI	quality indicator
RFP	request for proposals
RWJF	Robert Wood Johnson Foundation
SEER	Surveillance, Epidemiology, and End Results Program
SIOP	International Society of Paediatric Oncology
SSRI	selective serotonin reuptake inhibitor
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment
THC	tetrahydrocannabinol
VA	Department of Veterans Affairs
VNSNY	Visiting Nurse Service of New York
WHO	World Health Organization

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