

IMPROVING PALLIATIVE CARE FOR CANCER—NRC REPORT

Kathleen Foley, M.D.
Attending Neurologist
Memorial Sloan-Kettering Cancer Center
Professor of Neurology, Neuroscience, and Clinical
Pharmacology
at Weill Medical College of Cornell University
New York, NY 10021

Robert Wittes, M.D.
Deputy Director for Extramural Science Director
Division of Cancer Treatment and Diagnosis
National Cancer Institute
31 Center Drive
Building 31, Room 3A44
Bethesda, MD 20892-2440

**National Cancer Policy
Board Report
2001**

www.iom.edu

Improving Palliative Care for Cancer

National Cancer Policy Board Report 2001

Part I: Summary and Ten Recommendations

Part II: Eight Commissioned Chapters

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 2

**Reliable, High Quality Efficient End of
Life Care for Cancer Patients:**

Economic Issues And Barriers

Joanne Lynn and Ann O'Mara

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 3

**Quality of Life and Quality Indicators for
End of Life Cancer Care:**

**Hope for the Best, Yet Prepare for the
Worst**

Joan M. Teno

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 4

The Current State of Patient and Family Information About End of Life Care

Aaron S. Kesselheim

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 5

Palliative Care for African-Americans
and Other Vulnerable Populations:

Access and Quality Issues

Richard Payne

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 6

End of Life Care:

Special Issues in Pediatric Oncology

Joanne M. Hilden, Bruce P.

Himmelstein, David R. Freyer,

Sarah Friebert, and Javier R. Kane

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 7

**Clinical Practice Guidelines for the
Management of Psychosocial and
Physical Symptoms of Cancer**

**Jimmie C. Holland and
Lisa Chertkov**

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 8

Cross-Cutting Research Issues:

A Research Agenda for Reducing
Distress of Patients with Cancer

Charles C. Cleeland

National Cancer Policy Board Report 2001

Part II Eight Commissioned Papers

Chapter 9

Professional Education in Palliative and End of Life Care for Physicians, Nurses, and Social Workers

Hellen Gelband

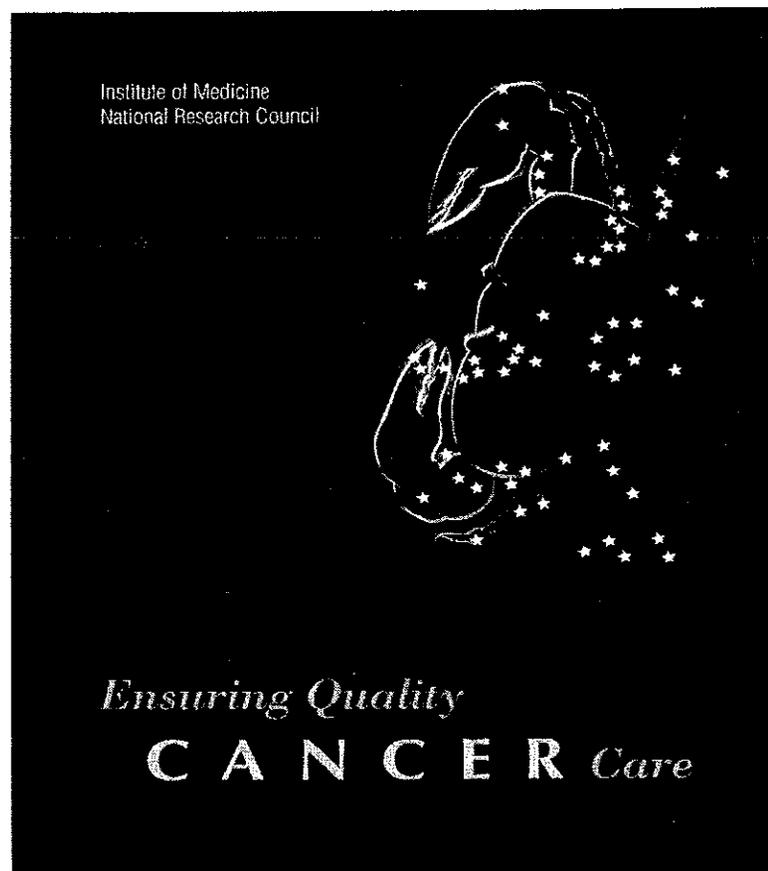
Builds on Previous Work

IOM 1997: *Approaching Death:
Improving Care at the End of Life*

www.nas.edu/iom

National Cancer Policy Board Report 1999

**“RECOMMENDATION 5:
Ensure quality of care at
the end of life, in
particular, the
management of cancer-
related pain and timely
referral to palliative and
hospice care.”**



Barriers to Excellent Palliative and Hospice Care

- Separation of palliative and hospice care from potentially life-prolonging treatment
- Inadequate healthcare professional training
- Disparities in care
- Lack of information resources for the public on palliative care and end of life care

Barriers to Excellent Palliative and Hospice Care

- Lack of reliable data on:
 - quality of life
 - quality of care
- Lack of accountability for providing quality care
- Low level of public sector investment in palliative care research and training

Medicare Hospice Benefit

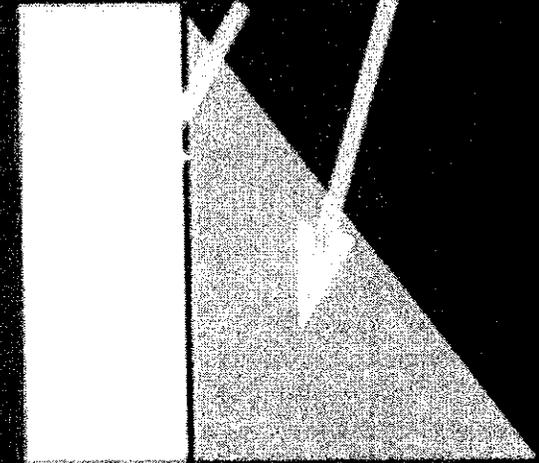
Disease-modifying Therapy

(curative, restorative)



Presentation

Hospice Care



6m

Death &
Bereavement

A New Vision of Hospice Care

**Modifying Therapy,
Curative, restorative intent**

Life
Closure

Risk

Condition

Death &
Bereavement

**Hospice Care
Palliative intent**

1998 ASCO Survey in End of Life Care

Emmanuel, et al

Hilden, et al

Survey: 118 questions

6,645 oncologists surveyed

74% response rate

1998 ASCO Survey in End of Life Care

Response Rate Among Specialties

	Medical Oncologists	Surgical Oncologists	Radiation Oncologists	Pediatric Oncologists
Eligible	5010	499	703	371
Responders	2129	128	203	172
Response Rate, %	42.5	25.7	28.9	46.4

1998 ASCO Survey in End of Life Care

Emmanuel, et al
Hilden, et al

- Most report inadequate training
 - 1/3 report formal training “very helpful”
 - 56% report “trial and error” as learning source
 - 45% report role models as important
- Traumatic patient experiences - high source of learning

1998 ASCO Survey in End of Life Care

Emmanuel, et al

Hilden, et al

- 25% report EOL as highly satisfying
- 40% report EOL as intellectually satisfying
- 63% report EOL as emotionally satisfying
- 10% report a sense of failure with dying patient
- 10% report anxiety and strong emotions with dying patient

1998 ASCO Survey in End of Life Care

Emmanuel, et al

Hilden, et al

Physicians Reporting Competency in Managing Symptoms

95% - pain

91% - constipation

93% - nausea & vomiting

89% - fever & neutropenia

79% - dyspnea

63% - anorexia

57% - depression

1998 ASCO Survey in End of Life Care

Emmanuel, et al
Hilden, et al

Barriers to Providing End of Life Care

56% - no available palliative care team

28% - no available hospital based hospice

18% - no available pain service

17% - have outpatient symptom control
services

1998 ASCO Survey in End of Life Care

Emmanuel, et al

Hilden, et al

26% - inadequate reimbursement for dying
conversation

41% - lack of coverage for non-skilled home
healthcare worker

- - lack of referral restrictions and coding
categories

1998 ASCO Survey in End of Life Care Case Vignette

A patient who “failed first time chemotherapy” with locally advanced lung cancer.

3% - recommended hospice

97% - Additional chemotherapy
(paclitaxel or phase I)

1998 ASCO Survey in End of Life Care Case Vignette

after failing paclitaxel

19% - refer to hospice

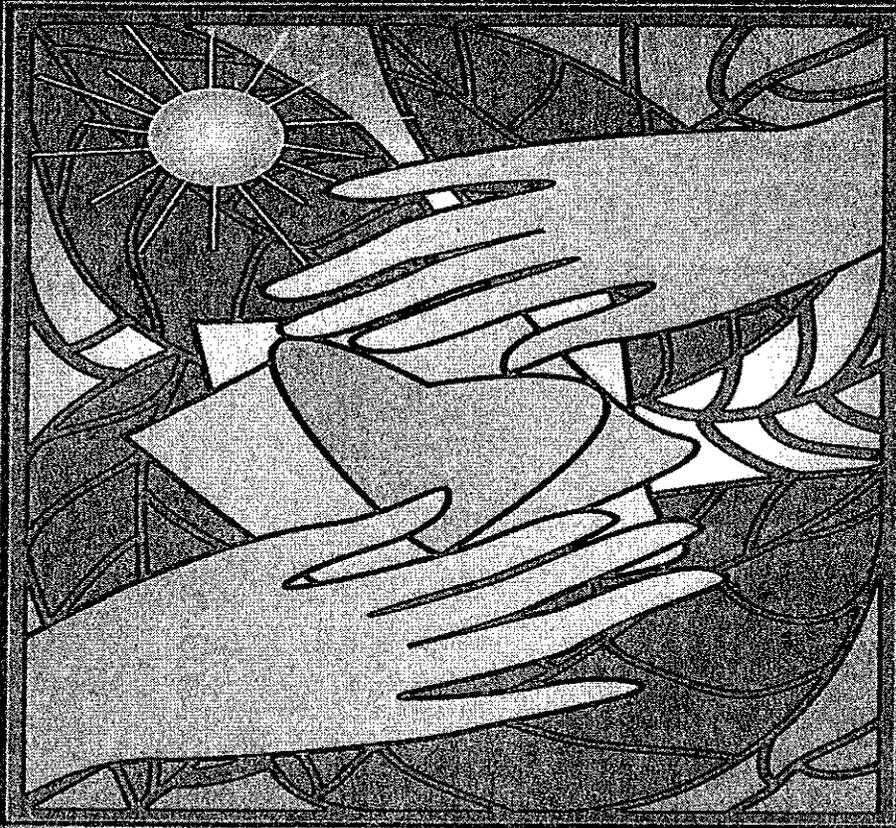
after failing third-line chemotherapy

20% - consider additional chemotherapy

Findings and
Recommendations
from
*Improving Palliative Care
for Cancer*

Improving Palliative Care for Cancer

S U M M A R Y A N D R E C O M M E N D A T I O N S

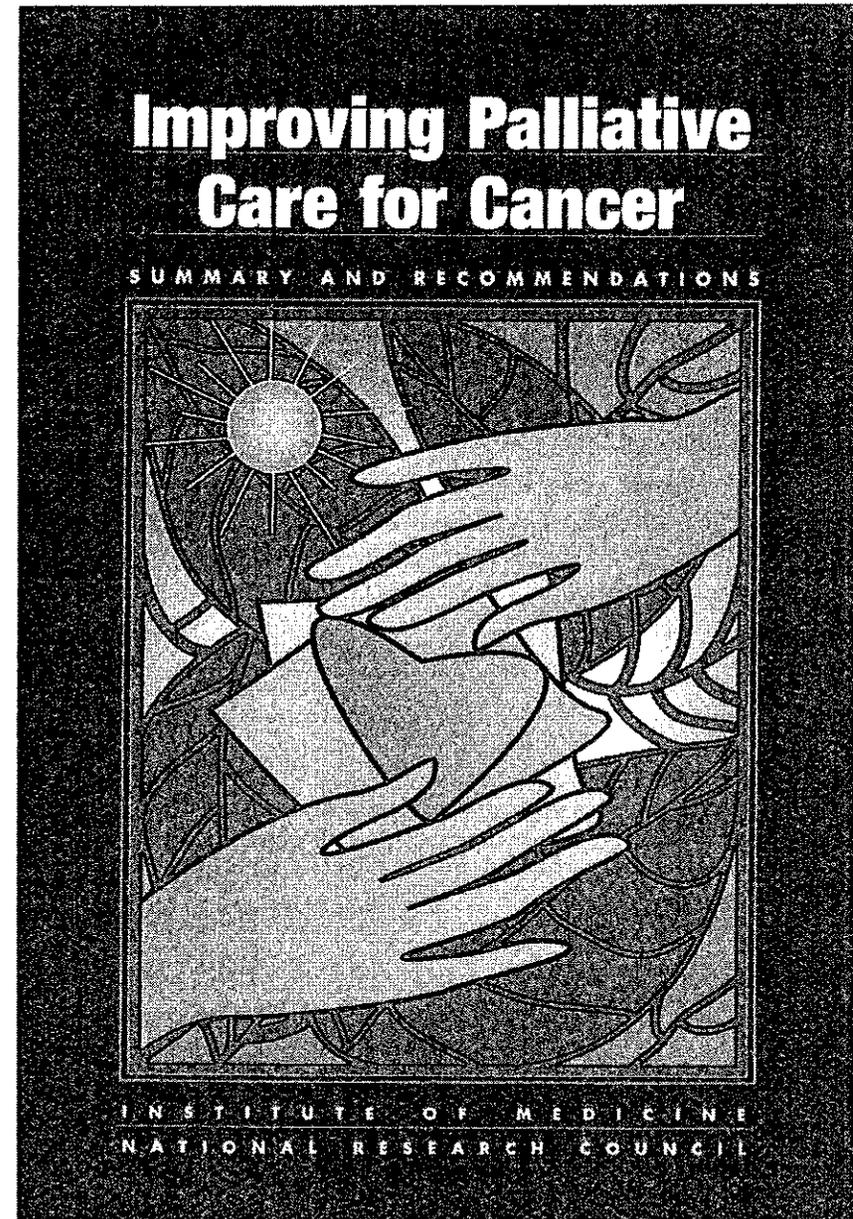


I N S T I T U T E O F M E D I C I N E
N A T I O N A L R E S E A R C H C O U N C I L

“NCI-designated cancer centers should play a central role as agents of national policy in advancing palliative care research and clinical practice, with initiatives that address many of the barriers identified in this report.”

Recommendation 1:

NCI should designate certain cancer centers, as well as some community cancer centers, as centers of excellence in symptom control and palliative care for both adults and children. The centers will deliver the best available care, as well as carrying out research, training, and treatment aimed at developing portable model programs that can be adopted by other cancer centers and hospitals.



Recommendation 1 (cont.)

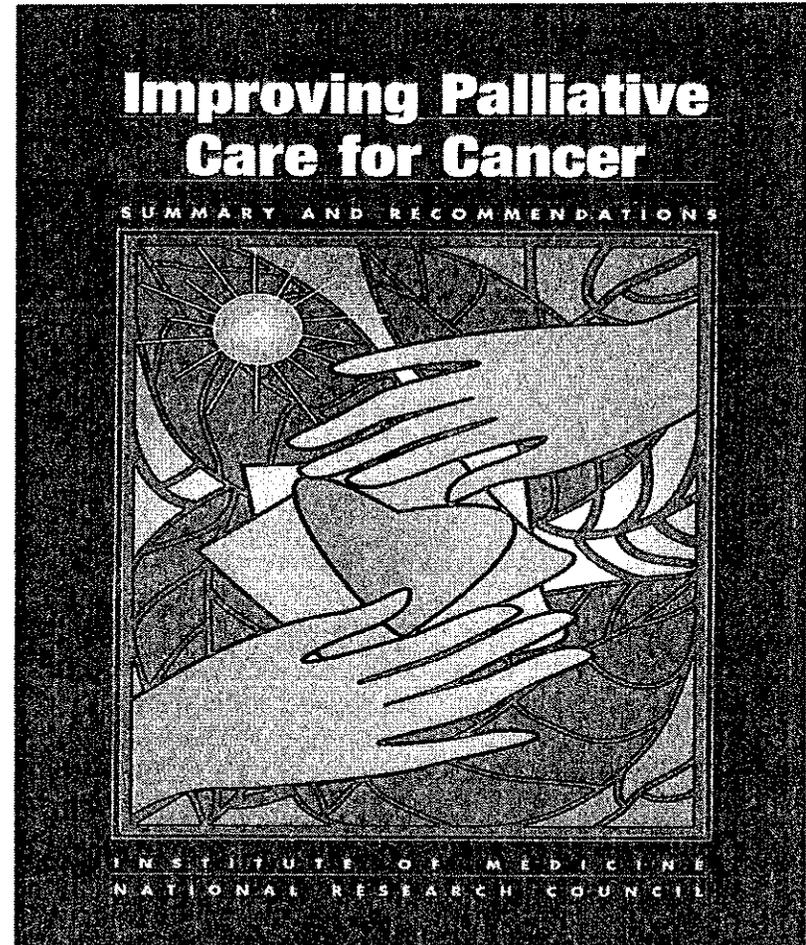
- *Test and evaluate practice guidelines*
- *Pilot test “quality indicators”*
- *Incorporate best palliative care into NCI-sponsored clinical trials;*
- *Innovate in care delivery, including collaboration with hospice organizations;*

Recommendation 1 (cont.)

- *Uncover determinants of disparities in access to care and develop initiatives to increase access;*
- *Provide clinical and research training fellowships*
- *Create faculty development programs*
- *Provide in-service training for local hospice staff*

Recommendation 2:

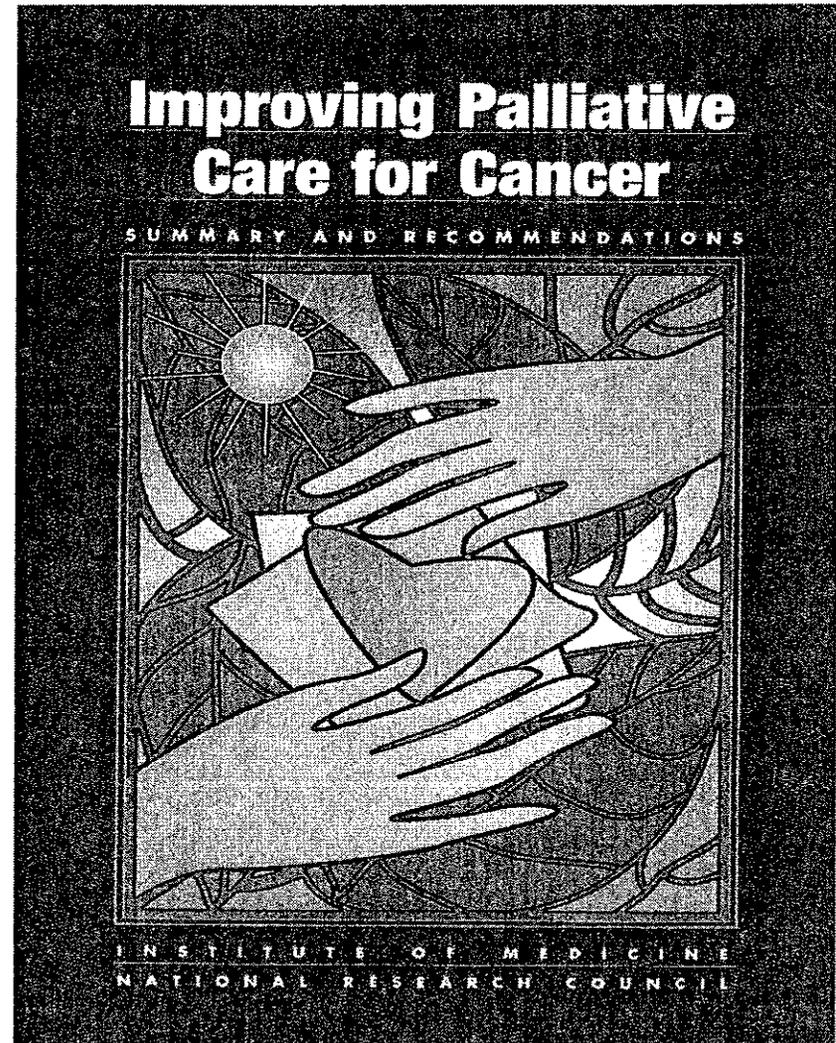
NCI should add the requirement of research in palliative care and symptom control for recognition as a “Comprehensive Cancer Center.”



“Practices and policies that govern payment for palliative care (in both public and private sectors) hinder delivery of the most appropriate mix of services for patients who could benefit from palliative care during the course of their illness and treatments.”

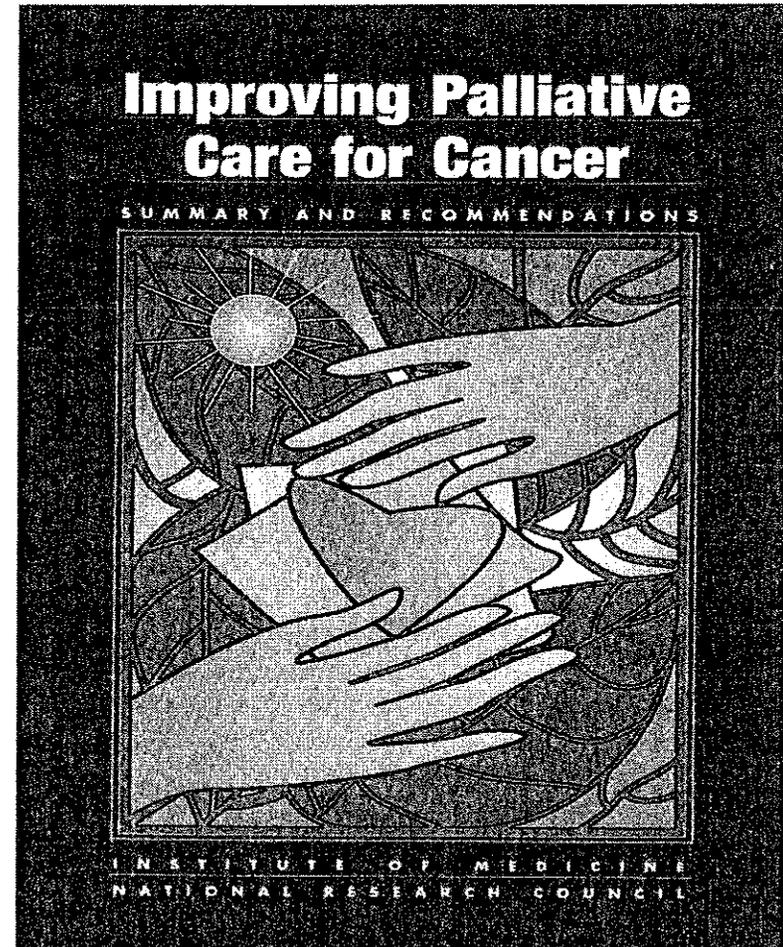
Recommendation 3:

The Health Care Financing Administration (HCFA) should fund demonstration projects for service delivery and reimbursement that integrate palliative care and potentially life-prolonging treatments throughout the course of disease.



Recommendation 4:

Private insurers should provide adequate compensation for end-of-life care.



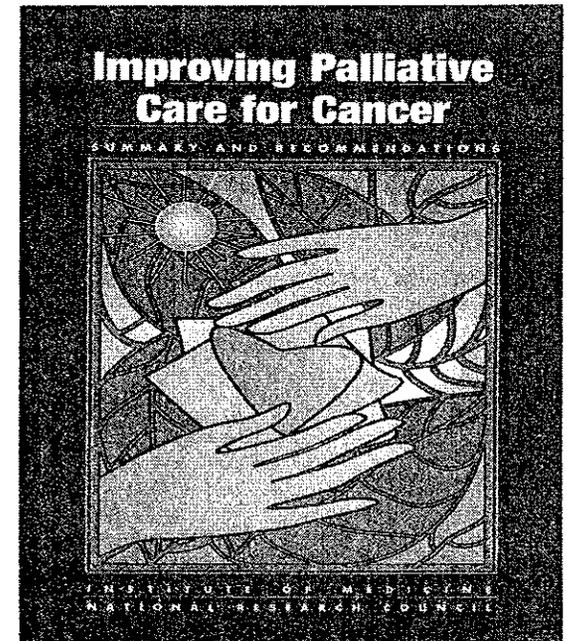
Recommendation 4 (cont.)

The special circumstances of dying children—particularly the need for extended communication with children and parents, as well as health care team conferences—should be taken into account in setting reimbursement levels and in actually paying claims for these services when providers bill for them.

“Information on palliative and end-of-life care is largely absent from materials developed for the public about cancer treatment. In addition, reliable information about survival from different types and stages of cancer is not routinely included with treatment information.”

Recommendation 5:

Organizations that provide information about cancer treatment (NCI, the American Cancer Society, and other patient-oriented organizations [e.g., disease-specific groups], health insurers and pharmaceutical companies) should revise their inventories of patient-oriented material, as appropriate, to provide comprehensive, accurate information about palliative care throughout the course of disease.



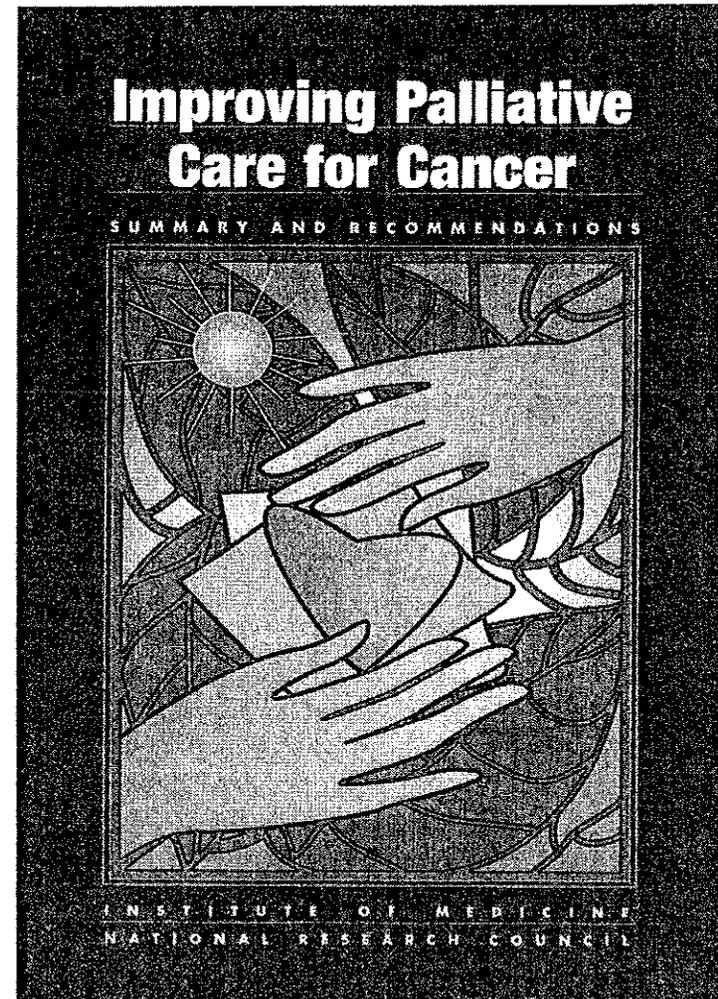
Recommendation 5 (cont.)

Patients would also be helped by having reliable information on survival by type and stage of cancer easily accessible. Attention should be paid to cultural relevance and special populations (e.g., children).

“Practice guidelines for palliative care and for other end-of-life issues are in comparatively early stages of development, and quality indicators are even more embryonic. Progress toward their further development and implementation requires continued encouragement by professional societies, funding bodies, and payers of care.”

Recommendation 6:

Best available practice guidelines should dictate the standard of care for both physical and psychosocial symptoms. Care systems, payers, and standard-setting and accreditation bodies should strongly encourage their expedited development, validation, and use.



Recommendation 6 (cont.)

Professional societies, particularly the American Society of Clinical Oncology, the Oncology Nursing Society, and the Society for Social Work Oncology, should encourage their members to facilitate the development and testing of guidelines and their eventual implementation, and should provide leadership and training for nonspecialists, who provide most of the care for cancer patients.

Clinical Practice Guidelines for End of Life Care

NCCN Guidelines:

Palliative Care (pending)

Doctor – Patient Communication (pending)

Distress

Delirium

Depressive Disorders

Anxiety Disorders

Clinical Practice Guidelines for End of Life Care

NCCN Guidelines:

Personality Disorders

Social Problems: practical or psychosocial

Spiritual or religious problems

Pain

Fatigue

Nausea & Vomiting

Status of Quality Indicator Development for End of Life Care

Domain	Proposed Indicators	Readiness
Pain	<p>Frequency and severity of pain from Minimum Data Set</p> <p>Patient and family perspective on pain management</p>	<p>Proposed indicators require validation, but can be measured for all hospitalized cancer patients</p> <p>Major limitation: captures only health care provider perspective</p> <p>Instruments available (e.g., from American Pain Society or Toolkit of Instruments to Measure End of Life Care)</p>

Status of Quality Indicator Development for End of Life Care

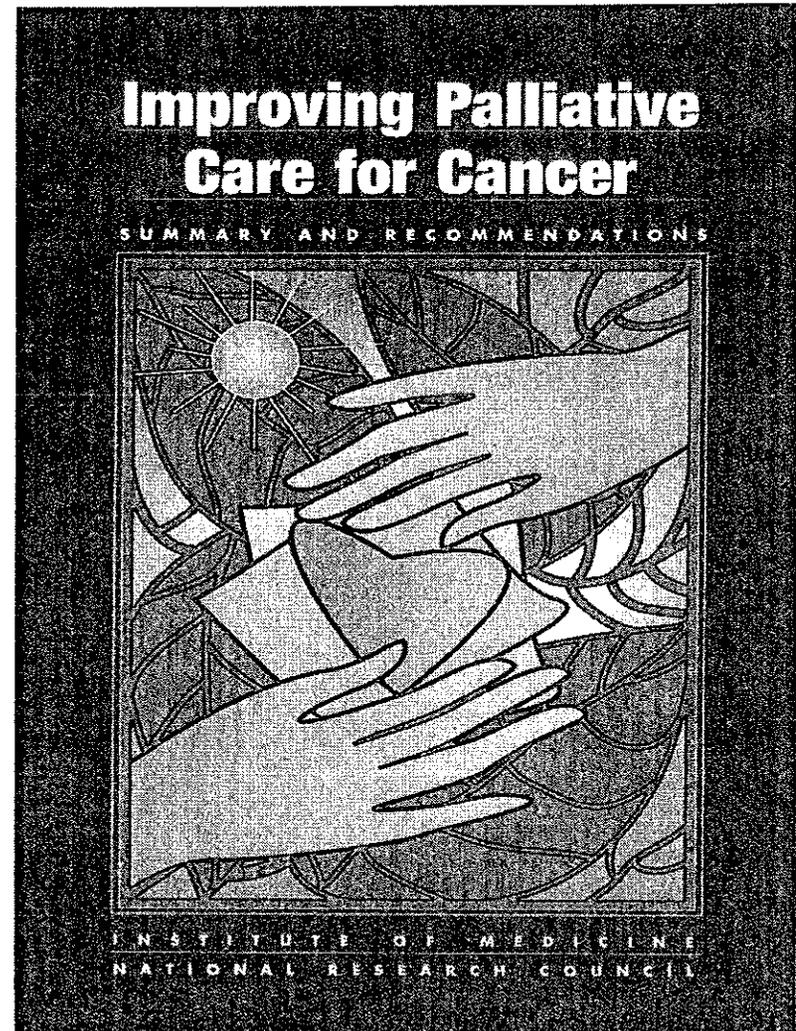
Domain	Proposed Indicators	Readiness
Satisfaction	<p>Measures of patient satisfaction, based on patient or surrogate responses</p> <p>New instruments include some questions relevant to people dying from cancer</p>	<p>New instruments have undergone reliability and validity testing. Additional questions are specific for cancer (e.g., whether patients are informed of recommended treatments, access to high-quality clinical trials) and incorporation into ongoing data collection efforts</p>

Status of Quality Indicator Development for End of Life Care

Domain	Proposed Indicators	Readiness
Shared Decisionmaking	Questions from Toolkit of Instruments to Measure End of Life Care	Reliability and validity testing completed Examination of responsiveness not complete
Coordination and Continuity of Care	No indicators yet available	

Recommendation 7:

The recommendations in the NCPB report, “ENHANCING DATA SYSTEMS TO IMPROVE THE QUALITY OF CANCER CARE” should be applied equally to palliative and end-of-life care as to other aspects of cancer treatment:



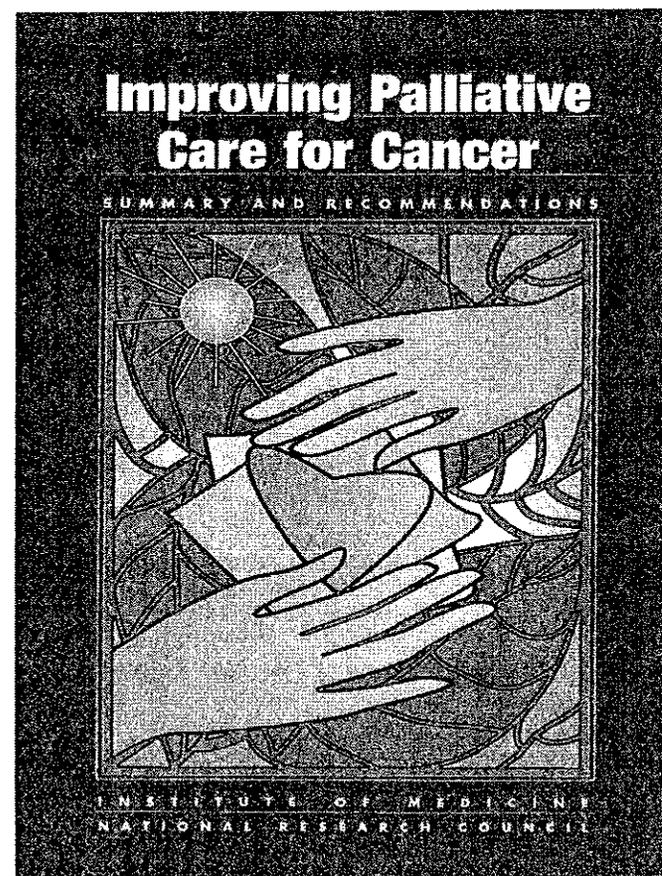
- *increasing support for cancer registries;*
- *new mechanisms for cancer care quality data;*
- *core set of cancer care quality measures;*
- *technologies to improve clinical data to assess quality of cancer care;*

- *training in health services research, other fields*
- *support health services research*
- *models for linkage studies*
- *demonstration projects on impact of quality monitoring programs*

“Research on palliative care for cancer patients has had a low priority at NCI and as a result, few researchers have been attracted to the field and very few relevant studies have been funded over the past decades. NCI should continue to collaborate with the National Institute of Nursing Research on end-of-life research (the lead NIH institute for this topic), but cannot discharge its major responsibilities in cancer research through that mechanism.”

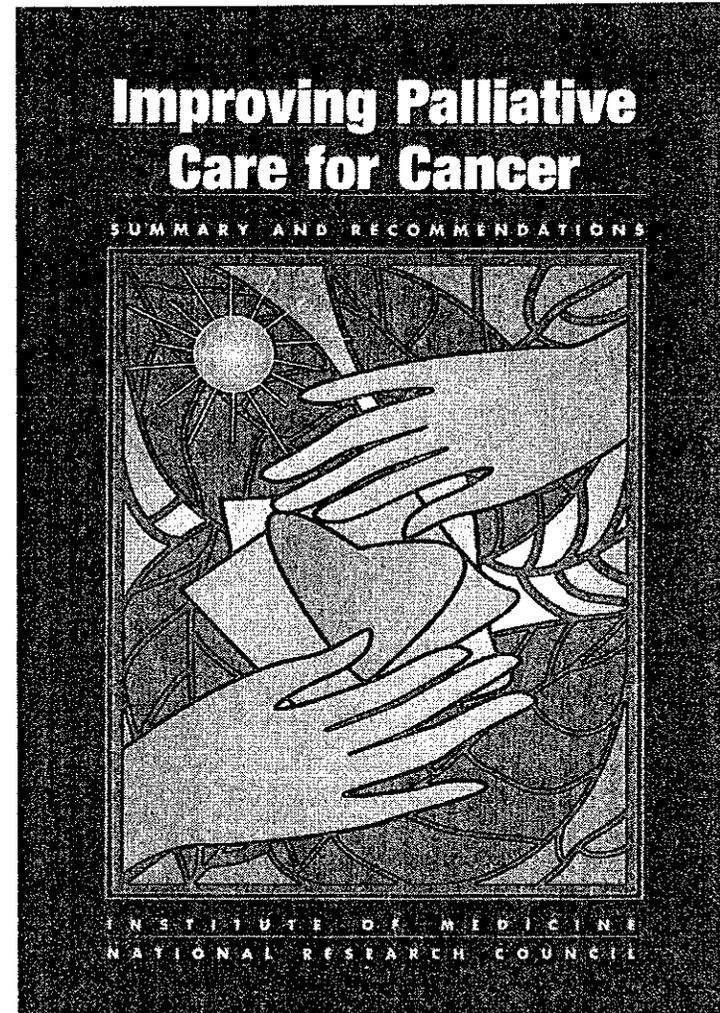
Recommendation 8:

NCI should convene a “STATE OF THE SCIENCE MEETING” on palliative care and symptom control. It should invite other National Institutes of Health and other government research agencies with shared interests should be invited to collaborate. The meeting should result in a high-profile strategic research agenda that can be pursued by NCI and its research partners over the short and long terms.



Recommendation 9:

NCI should establish the most appropriate institutional locus (or more than one) for palliative care, symptom control, and other end-of-life research, possibly within the Division of Cancer Treatment and Diagnosis.



Recommendation 10:

NCI should review the membership of its advisory bodies to ensure representation of experts in cancer pain, symptom management, and palliative care.

