COPY

NBCHPN
National Board for Certification
of Hospice and Palliative Nurses

Penn Center West One
Suite 229
Pittsburgh, PA 15276

Phone: 412-787-1057
Fax. 412-787-9305
E-mail NBCHPN@HPNA.org

September 30, 2003

Mr. Donald S. Clark
Office of the Secretary
Federal Trade Commission (FTC)
600 Pennsylvania Avenue, N.W.
Washington, D.C. 20580

Attention: David Hyman, Special Counsel to the FTC

Re: NBCHPN Response to Hearings on Health Care and Competition Law and Policy Regarding Advanced Practice Registered Nurse Task Force of the National Council for State Boards of Nursing, Inc.

The National Board for Certification of Hospice and Palliative Nurses ("NBCHPN") welcomes this opportunity to provide comments regarding the activities and determinations of the National Council for State Boards of Nursing, Inc. ("NCSBN") and NCSBN's Advanced Practice Registered Nurse Task Force ("APRN Task Force"). At this time, NBCHPN wishes to addresses several concerns identified in the June 2003 testimony of the National Association of Clinical Nurse Specialists ("NACNS") to the FTC and several points made in the July 31, 2003 NCSBN comments to the FTC.

NBCHPN recognizes and appreciates the critical services NCSBN provides to the national nursing profession. NCSBN offers a valuable service in the development and administration of the NCSBN NCLEX examination. Additionally, NCSBN serves as a national resource for nursing licensure and regulatory bodies.

Unfortunately, however, the effect of NCSBN's activities and determinations is a virtually insurmountable barrier to practice for individuals certified by NBCHPN and the American Nurses Credentialing Center ("ANCC") as advanced practice palliative care nurses. As such, this barrier also restricts the ability of ANCC and NBCHPN to compete in the field of nurse specialty certification.

By way of background, our concerns arise out of the following factual developments:

1. ANCC and NBCHPN jointly developed the advanced practice certification program for palliative care nurses (referred to herein as the "Certification Program").

2. ***The process followed by NBCHPN and ANCC in developing the Certification Program was substantially the same as the process followed by NCSBN in developing the examinations marketed by NCSBN.*** The Certification Program was developed out of grant funds from the Soros Foundation and the New York University School of Nursing. These funds offset the costs of preparing a psychometrically valid job analysis survey that demonstrates that the Certification Program's concentration is a separate and very distinct *specialty*. The job analysis also demonstrates that the *specialty field* of advanced practice palliative care nursing includes both nurse practitioners and clinical nurse specialists. It is important to note that the job analysis survey was developed and conducted under the supervision of highly recognized professionals, educators and employers in the field. Further the survey instrument, job analysis study, and examination questions and forms were all prepared under the direction of qualified psychometricians, as overseen by the Content Expert Panel. Attachment A is a summary of the qualifications of the Content Expert Panel. The Content Expert Panel performed under the guidance and review of Dr. David Paulson, the psychometrician who oversaw the entire process of developing the Certification Program.

3. Despite the noteworthy expertise involved in the development of the Certification Program, the NCSBN APRN Task Force made the following determinations to NCSBN regarding the Certification Program:

- *Palliative care is considered a subspecialty and not appropriate for entry into advanced practice. The scope is too narrow to form the basis for advanced practice.*

- *The category of successful candidate is not specified (NP or CNS). This may be problematic for boards of nursing that require APRNs to be licensed according to categories (e.g., nurse practitioner, clinical nurse specialist, etc.)*

- *A master's degree from a CNS or NP education program may be used in place of a graduate education program in palliative care. The required 500 hours of direct clinical practice can be acquired as a CNS or NP. Neither the level of practice nor the quality require3ments(sic) of the clinical mentor are specified.*

4. These determinations were made by the APRN Task Force following several conversations with the Co-Chair of the Credentialing Program's Content Expert Panel. However, these determinations were entirely contrary to: a) the determinations of the advanced practice palliative care Content Expert Panel,

which found that, in the specialty of advanced practice palliative care nursing there was not a psychometrically supportable distinction between the CNS or NP; and b) the psychometrically developed job analysis which demonstrated that the advanced practice palliative care nursing is a separate and distinct specialty, not subspecialty. In summary, the APRN Task Force made the above determinations contrary to the noted experts in the palliative care field and contrary to the academic authorities in the universities that train and prepare advanced practice palliative care nurses. The APRN Task Force determinations were made by individuals who completely (and without reasonable explanation) disregarded the only valid evidence of palliative care as being a separate specialty of both Clinical Nurse Specialists and Nurse Practitioners.

At its 2003 annual delegate conference, NCSBN distributed a July 30, 2003 memorandum to NCSBN's member boards regarding "Current CNS Issues." The final page of that memorandum indicates that NCSBN has adopted the position of the APRN Task Force regarding palliative care, as follows:

> After the APRN Uniform Core Requirements were approved, there were rapid changes in the field of advanced practice nursing. Most valid specialty areas developed a certification program through examination and educational programs began developing new subspecialty programs, such as 'pain management' and 'palliative care'.

Again, the characterization of advanced practice palliative care as being a "subspecialty," is entirely incorrect, unreasonable, and contrary to the leading experts in the field. Attachment B is a draft version of the Voluntary Consensus Standards for Quality Palliative Care ("Consensus Standards"). These draft Consensus Standards are the product of extensive research and surveys of the palliative care field. The Consensus Standards evolved from a collaboration of the following leading hospice and palliative organizations:

- American Academy of Hospice and Palliative Medicine
- Center to Advance Palliative Care
- Hospice and Palliative Nurses Association
- Partnership for Caring
- National Hospice and Palliative Care Organization

The Consensus Standards clearly define and recognize palliative care as a specialty, not subspecialty. Further, the Consensus Standards demonstrate how palliative care covers the entire life-span of the patient and encompasses all major areas of practice utilized by advance practice nurses.

Having demonstrated that the determinations of the APRN Task Force were in error, we will now outline the *effect* of these errors and NCSBN's activities on the Certification Program and its certified practitioners.

In a nutshell, the APRN Task Force determinations and NCSBN's position have the effect of increasing the restrictions on our advanced practice palliative care nursing certificants from practicing in their certified field. Simply stated, state licensing boards will almost assuredly adopt (in whole or part) the position of the APRN Task Force and NCSBN. Consequently, we expect that our Certification Program activities will suffer. Candidates are unlikely to work towards meeting eligibility requirements, and siting for a certification examination for a credential that is not likely to be recognized by state licensing boards. Universities that are developing programs of studies for advanced practice palliative care nursing will be disinclined to continue those activities. If their graduates are restricted from practicing in the field, the feasibility of offering such a program of study becomes a critical issue. If there are no qualified graduates, then the Certification Program will fold.

Of course we could separately petition individual state licensure boards to request that they disregard the determinations of NCSBN. As you can imagine, this would be a cost prohibitive and (in all likelihood) unsuccessful endeavor. The weight given to NCSBN determinations by state licensing boards is daunting. State licensure boards have come to rely on and accept (in whole or in part) the general recommendations of NCSBN in issues involving nursing fields of practice.

The unfair and unreasonable impact of the APRN Task Force determinations and the erroneous statements regarding the Certification Program has serious consequences for the Certification Program. Unfortunately, NCSBN does not offer a detailed process for petitioning for reconsideration the erroneous conclusions of the APRN Task Force. As you can see from the selected provisions of NCSBN's Bylaws (Attachment C), the NCSBN membership is limited to licensing boards that utilize the NCSBN NCLEX examination. Further, although the public is permitted to attend the annual delegate's conference, only NCSBN member boards approve resolutions for submission to the delegate assembly.

Since our Certification Program is a new program (implemented earlier this year), we are unable to demonstrate the effect of the APRN Task Force determinations on our number of certificants. Common sense, however, makes it apparent that NCSBN determinations of this nature can toll a death knell for an otherwise valid and psychometrically supported certification initiative. These devastating effects are felt throughout the palliative nursing community, especially by evolving academic programs for advanced practice palliative care nursing. The outcomes will likely reach to hospital, long term care and community based hospice and palliative care programs that have already identified a critical need for advanced practice palliative care nurses and that anticipate a steadily increasing need in the near future.

Absent minimum due process procedures for appealing the erroneous determinations, and/or a direct avenue to address our concerns with the entire NCSBN delegate assembly, our only recourse would be individual, state-by-state lobbying for changes to the nursing licensure laws. As aforementioned, this option is a cost prohibitive alternative that will most likely fail in light of the deference state licensing boards afford NCSBN determinations.

In conclusion, we appreciate the opportunity to address our concerns regarding the activities of NCSBN and the determination of the NCSBN APRN Task Force. As you can see, it is unreasonable and unfair for NCSBN to wholly disregard the determinations of the Certification Program's content experts and psychometricians. Again, we wish to emphasize that the process followed in developing the Certification Program was substantially identical to the process NCSBN utilizes in developing the examinations marketed by NCSBN. Further, NCSBN, as the primary avenue for addressing national state licensure issues, creates an insurmountable barrier to our Certification Program's activities and the practices of our certificants when NCSBN issues an erroneous determination. The damage caused by this determination is aggravated by the fact that the erroneous determination by NCSBN is not subject to appeal or reconsideration on a national level.

Thank you for your consideration of these comments.

Sincerely,

Jeanne M. Martinez, RN, MPH, CHPN
NBCHPN President
On Behalf of the Board of Directors of the
National Board for Certification of Hospice
and Palliative Care Nurses

ATTACHMENT A

BACKGROUNDS AND QUALIFICATIONS OF THE CONTENT EXPERT PANEL FOR THE ADVANCED PRACTICE PALLIATIVE CARE CERTIFICATION EXAMINATION

Members of the Content Expert Panel (CEP) of the Advanced Practice Palliative Care Certification Examination are recognized as experts in Palliative Care based on their advanced knowledge, skills, and leadership in the specialty.

CO-CHAIRPERSON: DR. PATRICIA HINCHLIFFE BERRY

Dr. Berry's dissertation study focused on "The Pain of Terminal Cancer in the Nursing Home." She received a predoctoral fellowship for Oncology Nurses. She is a Gerontological Nurse Clinician with a career-long commitment to hospice, palliative care, and pain and symptom management. She is a Certified Registered Nurse in Hospice (1996, 2000) and served as a hospice surveyor for the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), as well as a pain management consultant for JCAHO and other health care organizations. She has many years of experience as a hospice nurse and hospice coordinator.

Currently, Dr. Berry is faculty at the University of Utah, Salt Lake City, Utah. She has several board membership appointments such as for the International Journal of Palliative Nurse, the Wisconsin Pain Initiative and is a member of the International Association for the Study of Pain, the American Society of Pain Management for Nurses, the International Hospice Institute and College, the Hospice and Palliative Care Nurses Association, and the Oncology Nursing Society.

Dr. Berry has been invited to speak at numerous national conferences regarding JCAHO pain standards and pain assessment and management. Dr. Berry also has numerous publications related to palliative care and hospice nursing including a new textbook of which she is an editor entitled "End of Life Care: Clinical Practice Guidelines for Advanced Practice Nursing," published by WB Saunders.

CO-CHAIRPERSON: CAROL D. SPENCE, MS, RN, CHPN

Carol Spence, as the co-chair of the Content Expert Panel, is an advanced practice nurse with a specialty in psychiatric nursing. Carol currently is employed as a researcher for the National Hospice and Palliative Care Organization in Washington, DC. Her title is Senior Research Associate. Previous to this position, Carol has extensive experience in hospice and palliative nursing over the past decade. Carol has extensive knowledge of test development, administration and analysis having served on the National Board for Certification of Hospice and Palliative Nurses for the past four years. She earned the CHPN credential in 1995 and continues to be certified to the present. Carol graduated from Duke University with a BSN. She achieved her Masters in Nursing from the University of Maryland in 1998. She has continued in their doctoral program having completed all course work in the past year. She is currently working on her dissertation through this program. She is a member of the Sigma Theta Tau International Honor Society of Nursing.

CORRINE M. ANDERSON, MSN, RN, CS, GNP, CHPN

Corrine Anderson has extensive hospice and palliative experience for over 20 years. She is a diploma graduate from Broadlawn's Polk County Hospital School of Nursing in Des Moines, Iowa. She achieved her BSN and her MSN from the University of Texas in 1985 and 1999 respectively. Corrine is been a certified hospice and palliative nurse since the first testing in 1993. As a certified Geriatric Nurse Practitioner she has achieved an Advanced Practice Nursing License and a Limited Prescriptive Authority license in the state of Texas. She is currently employed as an Advanced practice Nurse for Palliative Care at Harris Methodist in Fort Worth, Texas. Corrine has extensive experience in exam development, administration and analysis having served on the initial National Board for Certification of Hospice and Palliative Nurses. As chairperson of the process, she was instrumental in accomplishing the first role delineation for the CHPN exam. Corrine has received numerous leadership honors and awards in the past decade and is widely published. She is a member of Sigma Theta Tau International Honor Society of Nursing.

MARGARET CAMPBELL

Margaret Campbell is an advanced practice nurse on the palliative care service of Detroit receiving Hospital, Detroit, MI. She leads this nurse-directed interdisciplinary palliative care team. Her background is as a clinical nurse specialist and nurse educator in critical care with a background in ethics. Ms. Campbell is a Fellow of the Academy of Nursing, recognized for her nursing leadership. She is currently a doctoral student in nursing at the University of Michigan. She has academic teaching responsibilities at Wayne State University School of Medicine regarding ethics and various end of life topics.

Ms. Campbell serves on many advisory boards related to palliative care and ethics and has received numerous awards for outstanding advanced practice nursing. She also has numerous publications related to end of life care and related issues, as well as in critical care nursing. She is a member of several nursing organizations, including the American Association of Critical Care Nurses. Ms. Campbell has participated on several research studies related to palliative care, and has presented the findings of such research at national meetings. She has numerous invited presentations on end of life care and related issues.

NESSA COYLE

Dr. Coyle has a Ph.D. in nursing and is an adult nurse practitioner. She is currently the director of the Supportive Care Program, Pain and Palliative Care Service, Memorial Sloan Kettering Cancer Center, New York. Her dissertation was a qualitative study regarding the experience of the dying. She is a fellow of the Academy of Nursing and has received numerous honors over her nursing career. Dr. Coyle is a member of several nursing organizations, such as the Hospice and Palliative Care Nurses Association, Oncology Nursing Society, American Pain Society, and International Work Group on Death, Dying and Bereavement.

Dr. Coyle serves as consultant on numerous palliative care initiatives nationally and internationally and is a member of the editorial board of several palliative care journals, including the Journal of Palliative Medicine, Journal of Pain and Symptom Management, and the Cancer Nursing Journal. Dr. Coyle has an extensive publication record in palliative care, and is co-editor of the "Textbook of Palliative Care Nursing," published in 2001 by Oxford Press.

PATRICK COYNE

Mr. Coyne's background is as a clinical nurse specialist in medical/surgical nursing. He is a Project on Death in American Faculty Scholar and is the Clinical Nurse Specialist in Pain and Palliative Care at the Medical College of Virginia. He is a nationally recognized expert in pain and palliative care and holds several consultant positions. He is a member of the End of Life Nursing Education Consortium Faculty and has written and taught the curriculum for this initiative both for undergraduate and graduate courses. Mr. Coyne is a member of several nursing organizations including Hospice and Palliative Nurses Association

Mr. Coyne is a board member of the National Board for Certification of Hospice and Palliative Care Nurses and on the Virginia Department of Health regarding cancer pain. He is involved in palliative care research and teaching and has been an invited speaker for numerous palliative care conferences. Mr. Coyne has numerous publications regarding hospice and palliative care nursing and is editor of new palliative care book which is in press regarding currently asked questions related to palliative care.

TERRI MAXWELL

Ms. Maxwell is an oncology clinical nurse specialist who is the executive director for the Center for Palliative Care at Thomas Jefferson University, Philadelphia, PA. She has many years of experience as a clinician and lecturer. She is Project on Death in America Faculty Scholar and Ph.D. Candidate in Nursing at the University of Pennsylvania. Ms. Maxwell is certified as an advanced practice oncology nurse and has additional education in pain and palliative care, attending the Harvard Medical School Palliative Care Course for Clinicians and Educators.

Ms. Maxwell has received several awards for excellence in nursing, and is an active member in several palliative care and oncology organizations. She has several publications in palliative care and has an extensive list of presentations in relation to palliative care nursing, most noted for her expertise in pain and symptom management.

KERSTIN L. MC STEEN, MSN, RN, CHPN

Kerstin McSteen is an advanced practice nurse currently working as a Palliative Care Nurse Specialist with the Allina End of Life Project at the Allina Hospice and Palliative Care in St. Paul, MN. Kerstin graduated from the University of Minnesota School of Nursing with a BSN and then continue to complete her MSN in 2002 as an Adult Health Clinical Nurse Specialist with a focus in hospice and palliative care. Kerstin has been a certified hospice and palliative nurse since 1995. She completed a Fellow in Palliative Care Medicine at the Harvard Medical School in 2000. She is a member of Sigma Theta Tau International Honor Society of Nursing since 2000. She is widely published and has presented numerous lectures over the past several years.

ROGER STRONG

Mr. Strong's background is as a Family Nurse Practitioner. He is currently a Ph.D. candidate in nursing. Mr. Strong is currently serving as a nurse practitioner, and acting team director for the San Diego Hospice, California. He has a background in HIV/AIDS nursing, serving as coordinator of the AIDS Resource Team of the Hospice with several local and national presentations related to AIDS care. Mr. Strong is a member of the Hospice and Palliative Care Nurses Association.

DEBORAH WITT SHERMAN

Dr. Sherman, associate professor with tenure in the Division of Nursing at New York University, coordinates the first nurse practitioner palliative care master's program in the US. Her background is in parent-child, critical care, and hospice nursing, and she is certified as an adult nurse practitioner. She received a Pre-doctoral Breast Cancer Research Fellowship and an Aaron Diamond Post-doctoral AIDS Research Fellowship.

In 1998, she was awarded the prestigious Project on Death in America Faculty Scholars Fellowship to implement the Palliative Care Master's Program at NYU, as well as a US Department of Health and Human Services grant to fund the Program.

Dr. Sherman has received an NCI grant, as principal investigator, to conduct a study entitled, "Interventions and Quality of Life for Patients with Cancer and AIDS and their Caregivers." Dr. Sherman is also a co-investigator on an NCI funded RCT to study psycho-social interventions for breast cancer patients and their partners. Dr. Sherman is a faculty member and practitioner for the Bronx Veterans Hospital Interdisciplinary Palliative Care Fellowship Program.

Dr. Sherman has numerous publications, presentations, and awards for excellence in scholarship and leadership. She is co-editor of the textbook "Palliative Care Nursing: Quality Care to the End of Life" and serves on several editorial boards, and as well as being faculty for the End of Life Nursing Education Consortium. She currently serves as a Steering Committee member for the National Consensus Project to develop the essential elements and best practices for palliative care, and has secured funding to develop the Advance Practice Palliative Care Credentialing Examination through the American Nurses Credentialing Center. Dr. Sherman has recently been elected as a Fellow to the American Academy of Nursing.

ATTACHMENT B

FIFTH ITERATION DRAFT OF THE VOLUNTARY CONSENSUS STANDARDS FOR QUALITY PALLIATIVE CARE

NATIONAL
CONSENSUS
PROJECT FOR
QUALITY
PALLIATIVE CARE

Inquiries to:
Mary Meyer
Project Director
(212) 870-2003 or after 4-25-03
(718) 622-0089
109 Cambridge Place
Brooklyn, NY 11238
mmeyer@nationalconsensusproject.org

August 28, 2003

Margaret Bloom
Bloom Law Office Bldg.
1250 Connecticut Avenue, NW #700
Washington, D. C. 20036

Dear Ms. Bloom,

It gives me great pleasure to share the fifth iteration draft of the Voluntary Consensus Standards for Quality Palliative Care, a product of the National Consensus Project (NCP). This project began in December, 2001 and has been developed through the NCP, a collaboration of five leading hospice and palliative organizations: the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), the Hospice and Palliative Nurses Association (HPNA), Partnership for Caring and the National Hospice and Palliative Care Organization. More than 100 individuals representing major experts and contributors to the specialty of hospice and palliative care have served in the role of advisors to this project including individuals such as Dennis O'Leary from the Joint Commission on Accreditation of Health Care Organizations and Ken Kiser from the National Quality Forum.

At this time, the fifth iteration draft has been distributed to all advisory members as well as all board members of the five leading organizations for their feedback. The final document will be published in December, 2003 and widely distributed throughout the United States in January, 2004. A massive media campaign is being developed to introduce these new standards.

Although the document is currently in draft stages, I hereby give permission for sharing it with the Federal Trade Commission as evidence of the establishment of interdisciplinary standards for the specialty of palliative care.

Sincerely,

Betty Ferrell PhD, FAAN

Betty Rolling Ferrell, PhD, FAAN
Chair, National Consensus Project Steering Committee

Cc: file

National Consensus Project for Quality Palliative Care: The Development of Voluntary Standards

DRAFT 5 8/25/03

Foreword

Palliative care services and hospice programs have grown rapidly in recent years in response to growth in the population living with life threatening illness and evidence of the need for attention to symptom distress, patient and family support and care coordination across settings. Palliative care aims to relieve suffering and support the best possible quality of life for patients with life threatening illness and their families. Interdisciplinary palliative care teams address complex problems in physical, psychological, familial, social and spiritual domains. Attention to these priorities is required from the day of diagnosis and through the full course of illness and bereavement. Therefore, palliative care may be effectively delivered in concert with appropriate curative and life prolonging therapies as well as when patients forgo such therapies, seeking comfort and support near life's end.

The initiative to create Voluntary Consensus Standards for Quality Palliative Care in the United States has its roots in a recent study by the National Hospice Work Group (NHWG) and the Hastings Center, in association with the National Hospice and Palliative Care Organization (NHPCO), as well as the recommendations of an Institute of Medicine (IOM) report, Approaching Death (Field & Cassel, 1997) and the American Association of Colleges of Nursing (AACN) report Peaceful Death (AACN year?). All three reports have called for substantive changes to improve access to and the delivery of palliative care in hospice and all health care settings and during all stages of life threatening illness. These changes included enhancements in the quality of care, health care system and organizational restructuring, service regulations, education of health care professionals, and research to support evidence-based palliative care practice. This document is a response to the recommendations in the NHWG/-Hastings Center/NHPCO, IOM and AACN reports.

The necessary integration of palliative and life-prolonging interventions is a major challenge for health care in the United States. Patients with palliative care needs must have access to primary healthcare practitioners who are knowledgeable about palliative therapies, as well as to interdisciplinary specialist-level palliative care clinicians. The effort to integrate palliative care into all medical care for life-threatening illness should ensure that:

1. Pain and symptom control, psychosocial distress, spiritual issues, and practical needs in the home are addressed for patient and family.
2. Patients and families obtain the information they need to understand their condition and treatment options; their values and goals are elicited; the benefits and burdens of treatment are continually re-assessed; and the care plan is adjusted to respond to these values and goals.

3. The patient and their family are prepared for death, support is available for the family afterward, hospice options are explored, and opportunities for closure and growth are enhanced.

It is in the interest of achieving these goals that the National Consensus Project for Quality Palliative Care established Voluntary Consensus Standards to guide the development and structure of new and existing clinical palliative care programs.

Definition of Palliative Care

Palliative care is a comprehensive, interdisciplinary specialty providing comfort measures and support for the physical, psychological, social, and spiritual needs of patients with a life-threatening illness and their families. When difficulties arise in the care of persons with life threatening illness, they are most often related to poorly controlled symptoms; conflicted or unclear goals of care; distress related to life-threatening illness, grief, loss, and bereavement; and increasing family burden. Palliative care therefore aims to ensure that physical comfort is a priority, practical care needs are addressed and coordinated, psychosocial and spiritual distress are managed, patient and family values and decisions are respected and determinative, and opportunities are available for growth and resolution. Palliative care is both a general approach to patient care that should be routinely integrated with disease modifying therapies, as well as a growing practice specialty for highly trained specialist physicians, nurses, social workers, chaplains, and others who typically work in interdisciplinary palliative care teams.

[Side bar or figure The World Health Organization (2003) defines palliative care as "an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process; Intends neither to hasten nor postpone death;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance the quality of life, and may also positively influence the course of a patient's illness" (WHO, 2003 http://www.who.int/hiv/topics/palliative/PalliativeCare, accessed 082503).

[END SIDEBAR OR FIGURE]

Fundamental principles and core values underlie palliative care and apply to palliative care service delivery regardless of program type or setting. Thus, the National Consensus Project definition of palliative care includes the following key elements.

- Patient population: The population of patients/family served includes patients and families experiencing a life-threatening illness (Field & Cassel, 1997; AACN year?).
- Patient and family centered care: The patient and family constitute the unit of care. The family is defined by the patient. In this context, family members may be related or unrelated to the patient; they are individuals who provide support and with whom the patient has a significant relationship. The processes of care are determined by the goals and preferences of the patient and family. (Krammer et al., 2001; NHPCO, 2000a).
- Timing of palliative care: Palliative care begins at the time of diagnosis of a life-threatening illness and continues across the illness trajectory, through death, and into the family's bereavement period (MacDonald, 2002; Portenoy, 1998, Ryndes, 1995).
- Comprehensive care: Palliative care employs comprehensive multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social, and spiritual distress. The care provided should regularly assist patients and their families in defining what is important to them, and provide adequate support to help them accomplish their goals (NHPCO, 2000a; Ternestedt, Andershed, et al., 2002). Palliative care standards assume the regular and formal clinical process of assessment, diagnosis, planning, interventions, and evaluation (NHPCO, 2000a). (Patterson & Dorfman, 2002; Steinhauser, Christakis, Clipp, et al, 2000; Kristjanson, 1997; Tolle, Tilden, et al., 2000; Kristjanson, 1997; NHPCO, 2000a;Lamberg, 2002; Ellershaw, Smith, et al., 2001; Finlay & Jones, 1995).
- Interdisciplinary team: Quality specialist-level palliative care relies on the interdisciplinary team as a key component of successful patient outcomes The team is skilled in identifying and achieving the goals established by the informed patient and family. Typical palliative care teams include physicians, nurses, social workers, volunteer coordinators, bereavement coordinators, chaplains and often also include pharmacists, nursing aides and home attendants, physical and occupational therapists, and trained volunteers. (CAPC, 2000; NHPCO, 2000a ; . Carducci et al, 1999; Francke, 2000;. Krammer et al., 2001; Coyle, 1997; Krammer et al., 2001; Cummings, 1998)
- Relief from suffering: Palliative care seeks to provide relief from pain, symptoms, and other sources of distress throughout the course of care for patients with life-threatening illnesses, and their families (NHPCO, 2000a; Thompson & McClement, 2002).

- Communication skills: Principles of patient- and family-centered communication are the foundation of effective palliative care, and include effective sharing of information, active listening, determination of goals and preferences, and attention to regular and coordinated opportunities for communication during interactions with patients and their families (Detmar, Muller, et al., 2001; Buckman year?; Larson & Tobin, 2000; NHPCO, 2000a).
- Skill in care of the dying and the bereaved: Palliative care specialist teams must be knowledgeable about the developmental stages of living with and dying from a life threatening illness, including grief, the opportunities for growth and closure, the process of dying, and the associated care needs of the dying person and the family (Meier, 2002; NHPCO, 2000a).
- Care in all settings: Palliative care is needed and appropriate wherever a patient and family with life threatening illness receives care, and is therefore integral to all health care delivery system settings (hospital, nursing home care, home care, outpatient and non-traditional environments). There should be coordination, communication, and continuity of palliative care across health care settings (Ferris, Balfour, et al., 2002; Friedman, Harwood, & Shields, 2002; Jennings et. al. 2003; Ryndes & Emanuel, 2003).
- Equitable access: There should be equitable access to palliative care across health care settings (Meier, 2002; NHPCO, 2000a; Smeenk, deWitte, et al, 2000).
- Quality improvement: The palliative care team must be committed to the pursuit of excellence in palliative care and the highest quality of care and support for all patients and their families. Determination of care quality requires measurement and evaluation of the quality of care provided by the palliative care program. (Ellershaw, Smith, et al., 2001; Teno, 2001; NHPCO, 2000a).

Models of Palliative Care Delivery

Palliative care is appropriate from the time a patient is diagnosed with a life-threatening illness (Portenoy 1998, Ryndes, 1995) and service delivery should be structured accordingly. Palliative care programs are most effective when structured to deliver palliative care in a manner that best meets the patient's needs in the specific care setting (Mann & Welk, 1997; Post & Dubler, 1997). This requires training both for practitioners in primary treatment settings, as well as development of and support for credentialed palliative care specialists. Palliative care specialists, in turn, should encourage the development of professional credentialing and accreditation of palliative care training programs.

Current models of palliative care include hospice care (see Appendix for a discussion of hospice care in the United States) and a broad array of emerging palliative care programs situated in hospice, home care, acute hospital, nursing home, and community settings. The unmet need for specialist-level palliative care in the United States can best be met by expanding hospice services to all those eligible, supporting the development of palliative care programs, creatively integrating hospice and palliative care programs across treatment settings, and defining appropriate accountability measures for palliative care programs. Outside of certified hospice programs, there are no practice or accountability standards for palliative care clinical programs in the United States. The National Consensus Project aims to correct this deficiency.

Emerging models for specialist-level palliative care delivery must be tailored to the needs of the institution, specific care setting, and local community. Palliative care programs must strive to incorporate an interdisciplinary team, support for the family including bereavement and practical help, continuity of care, and close collaboration with other professionals involved with the care of the patient.

Common organizational models for palliative care programs inclusive of hospice programs include:

- Consultation service team (usually in a hospital, office practice setting, nursing home, or home setting);
- Dedicated inpatient unit (acute and rehabilitation hospital, nursing home, or combined with free-standing in-patient hospice):
- Combined consultative service team and inpatient unit (hospital and nursing home)
- Combined hospice program and palliative care program (hospital, nursing home, and some freestanding hospice in-patient facilities)
- Hospital- or private-practice-based outpatient palliative care practice or clinic (CAPC, 2000; von Gunten, 2002b).
- Hospice-based palliative care at home
- Hospice-based consultation in outpatient settings

The Need for Further Expansion of Palliative Services

The need for expansion of access to palliative care services is underscored by data demonstrating a high prevalence of untreated or inadequately treated pain and other distressing symptoms in hospital, office practice, home care, and nursing home settings (Bernabei; SUPPORT; Cleeland). In addition, multiple studies have documented poor communication about the goals of care between health care practitioners, patients and family members (SUPPORT, 1995; Byock & Miles, 2003; Emanuel et al, 2002; Morrison et al, 2000). Despite the fact that over 90% of Americans say they would rather be cared for at home, over three quarters of deaths in the U.S. occur in hospitals (about 50%) or nursing homes (about 25%). (Dartmouth Atlas, 1998; Teno, 2003). Recent research has shown high family caregiver burden, as well as increased morbidity and mortality for the family members of patients with chronic and life-threatening illness (SUPPORT; Tolle, et al 2000; Schulz et al; Steinhauser). Finally, although the majority of medical and nursing clinical education occurs in hospital settings, it is widely recognized that medical and nursing education is currently insufficient to train practitioners with both the primary care and specialist skills required to provide quality medical care for the rapidly growing number of elderly and chronically ill patients with life-threatening illness (Wenger, Phillips, Teno, Oye, Dawson, Liu, et al., 2000; Tolle, Tilden, Rosenfeld, & Hickman, 2000; Novak, Kolcaba, Steiner, & Dowd, 2001; Murphy-Ende, 2001; Meisel, Snyder, & Quill, 2000;Lynn, 2000; Covinsky, et al., 1999; SUPPORT Principal Investigators, 1995; Field & Cassel, 1997).

This high prevalence of suffering, poor communication about care goals, and discontinuities of care occur despite the fact that both patients with life threatening illness and their families say that what they get from the health care system is precisely the opposite of what they want: to be free of physical distress; to have some control over decisions about their health care; to avoid death-prolonging treatments; and to improve relationships with and reduce burden on their families. (Singer Stienhauser Emanuel, Tolle) The failure to provide services consistent with patient's preferences demonstrates the need for increased access to quality palliative care in and across all settings of health care; closer working relationships between hospice programs and hospitals and nursing homes; improved awareness on the part of health professionals in these care settings about palliative care and hospice, and efforts to resolve regulatory constraints which create both real and perceived barriers to access.

While palliative care as regulated in certified hospice programs is offered to those with limited life expectancy who agree to forego disease-modifying treatments, in its broader definition, it is equally relevant to and needed by a large and growing population of patients who suffer from life threatening illnesses. To achieve this end, both palliative care and hospice programs must continue to respond to evolving community need and new palliative care delivery systems must be created to meet these needs. How this is provided will vary in communities, but the evidence base for the impact of hospice and palliative care demonstrates its benefits in a range of care settings in terms of reduction in symptom distress, improved patient and family satisfaction, reduction in hospital length of stay, costs, and utilization, and increased referral to and length of stay in hospice programs. (Schapiro et. al. 2003)

. SIDEBAR or INSERT

Urgency is critical, for the Urban Institute reports that "The nation is about to experience a great demographic shock. Between 2010 and 2030 the over 65 population will rise over 70 percent, while under current law the population paying payroll taxes will rise less than 4 %." (Burman et al, 1998). This snapshot of the aging baby boomer population, when aligned with progressively higher health care costs, diminishing labor and financial resources, insecurity of federal entitlements and longer life expectancies creates a dramatic projection of future health care needs. These factors, more than anything, illustrate the need for a highly effective continuum of palliative care. **END OF SIDEBAR**

The time has come to build on the experience base of relevant domestic and international models of hospice and palliative care-- and to identify core standards of practice that will encourage the development of new and existing programs outside of certified hospice programs. It is expected these core standards will eventually become the common requirements for any provider of comprehensive, high quality, palliative care in the United States.

Access to Palliative Care across the Continuum

The growth of interest in palliative care underscores the importance of voluntary standards aimed at promoting palliative care clinical services of a high and consistent quality in the United States. Because of the high prevalence of care for persons with life threatening illness in hospitals and nursing homes, a major focus of this document is on access to palliative care in these treatment settings.

In 1995-96, the likelihood of a hospitalized death was closely linked to hospital day rates and the number of hospital beds per 1,000 population (Prtichard et. al.1998). In one hospital referral region, fewer than 18% of Medicare deaths occurred in hospitals; in other regions, the proportion was almost 50% (www.dartmouthatlas.org). Lower hospital death rates have been linked, among other factors, to higher hospice utilization, (Tolle, 1999), suggesting that availability of high quality palliative care provides an alternative to hospitals as a place of care for the dying. We focus on hospitals and nursing facilities in this document because of the need for palliative care in these settings: virtually all persons with serious illness spend at least some time in a hospital, usually on multiple occasions, in the last year of life. Further, over half of persons over age 80 end their lives in a nursing home (cite needed). Data from numerous studies demonstrate high degrees of symptom distress in hospitalized and nursing home patients;[5, 6] high use of burdensome life-prolonging technologies among the seriously and terminally ill;[5] enormous caregiver burden on families;[7, 8] and poor-to-nonexistent communication about the goals of care between these patients, their families and their treating physicians.[5, 9]

In addition to serving as a principal location of care, hospitals are the primary training site for the nation's future health care professionals and are a key component in the current effort to improve palliative care. The nation's future physicians, nurses and other health care professionals will receive a significant part of their apprenticeship in a hospital. If we are to prepare our providers to respond to the various forms of human suffering, to know how to work with the medical system on behalf of patients and families, and to see care of the dying as well as the chronically and seriously ill as a core clinical responsibility, that teaching must occur at least in part in the hospital setting. From the nursing and medical student or houseofficer standpoint, if palliative care is not taught during clinical rotations in the hospital, then it is by definition not an important competency for a health professional to own.

In addition, while standards for palliative care clinical programs have a high degree of applicability in hospitals, focused efforts need to be made to improve the quality of life and quality of dying of Americans in nursing homes, where limited resources and staff turnover often make the provision of expert palliative care services difficult. Promotion of contractual relationships between nursing homes and hospices is a prevalent and growing model of palliative care delivery in the nursing home setting. (NHPCO cites) Compared to nursing homes without hospice relationships, homes with hospice relationships show significant reductions in hospitalizations, hospital lengths of stay, restraint use, use of injection analgesics, and insertion of intravenous lines and feeding tubes, as well as a higher likelihood of detection and treatment of pain . (Miller, 2000, pg. 11) Consequently, a nursing home's ability to provide the types of palliative services identified in this document may best be achieved through a contractual relationship with a local hospice.

Most patients and their families receive health care in multiple clinical settings: physician's offices, hospitals, nursing homes, and home care. Poor communication between these care settings and associated discontinuities of care are the norm (Morrison et al JAMA1995) rather than the exception in the United States (need more references). While discontinuity and fragmentation of care represent failures in any clinical setting, continuity of care is of especially critical importance for patients and families facing life-threatening illness. Continuity of palliative care promotes the communication of information, thus avoiding needless suffering, minimizing patient and family perceptions of abandonment, and promoting patient-directed care. (Ryndes & Emanuel, 2003). Continuity of care will be optimized for patients when palliative care is rendered consistently and competently in all health care settings, but to accomplish this important goal, it is also critical to establish a common vision and approach to care, not only within, but between care settings. (Jennings et. al. 2003). In order to promote continuity of care through a common approach, the growth of palliative care will be best served by a strong link between the Voluntary Consensus Standards for Quality Palliative Care and the Standards of Practice for Hospice Programs.

[SIDE BAR or INSERT for statistics below]
There is reason to be optimistic about improving access to palliative care services. As of 2002, more than 25 percent of academic medical centers[2] and well over 800 hospitals (about 20% of all hospitals in the U.S.) indicate they provide access to a palliative care program, including hospice.[3] Additionally, nearly a third of the 3,200 US hospices are hospital-based. In the last seven years, more than 1200 physicians have been certified as subspecialists by the American Board of Hospice and Palliative Medicine (ABHPM) and approximately 7,000 registered nurses, 43 advanced practice nurses and nearly 1,000 nursing assistants are certified in palliative care. Over the last three years, more than 1000 physicians and 1500 nurses have attended three-day long educational conferences sponsored by Education for Physicians in End-of-Life Care (EPEC) and End of Life Nursing Education Consortium (ELNEC). There are 42 postgraduate medical fellowship programs and 2 graduate nursing programs in palliative care across the country, and more are in planning stages.[4] In 2003 over 2300 clinicians attended the NHPCO-HPNA Joint Clinical Conference to advance their learning in hospice and palliative care and more than a thousand health professionals representing over 400 hospitals and hospices attended conferences sponsored by the Center to Advance Palliative Care aimed at helping health professionals and managers start and sustain palliative care programs.
[END of SIDE BAR or INSERT]

The Need for Consensus

The widely recognized value of hospice programs in the United States has stimulated the development of palliative care programs that aim to extend the hospice approach to the many patients and their families who, for a variety of reasons, might die in hospitals or nursing homes without the benefit of care from certified hospice programs. In order to improve access to reliable and high quality hospice and palliative care, consensus of leading professional organizations in the field on core standards for new and evolving clinical programs is required. The aim of these Voluntary Consensus Standards for Quality Palliative Care is to set the stage for standards which will promote quality and reduce variation in new programs, develop and encourage optimal use of hospice, and facilitate the integration of hospice and palliative care programs. (Pan; Billings and Pantilat).

Practice standards for palliative care in the United States have been pioneered by professionals within the modern hospice movement over the past 30 years and have resulted in well-regulated federal, state and commercial hospice benefits. These standards have also influenced the development of numerous palliative care programs, clinical services, and educational initiatives inside and outside the confines of hospice's reimbursement structure.

[SIDE BAR or INSERT]

In addition to the advent of insurance payment mechanisms for certified hospice programs, the growth of hospice in the United States is a reflection of demonstrated and growing clinical expertise and consistently favorable patient and family satisfaction ratings. Certified hospice programs have been delivering palliative care to the terminally ill in this country for 20 years, and dramatic increases both in number of programs and in number of patients served have been documented in recent years (cites). More than 885,000 patients and their families received hospice care in 2002, nearly a 15% increase over the prior year.

Currently, more than half of the patients in the US who die with a diagnosis of cancer opt for hospice care, while in some communities hospices care for over 90% of patients with cancer (www.nhpco.org). In addition, 50% of US hospice patients in 2002 had noncancer diagnoses.

[END SIDEBAR or INSERT]

Against this impressive record of steady growth in hospice services, however, large numbers of individuals who need and deserve expert symptom management, care coordination and adaptive counseling well before the final phase of illness face a variety of regulatory and knowledge barriers to accessing the services they need (Jennings et. al. 2003). Further, physicians, nurses and other professional caregivers who treat frail elderly patients with end-stage heart disease or advanced dementias are too often unaware of hospice as a choice, or are misinformed about the provisions of this option.

The hospice community has created the gold standard for end of life care. The health care community at large is now building on the experience of the hospice movement in order to extend the lessons learned in providing compassionate end of life care and to make this approach available to patients at any stage of a life threatening illness. In order to effectively promote palliative care of persons with life threatening illness across the continuum of care, professional consensus on the core standards of palliative care clinical programs is required. The mission of the National Consensus Project for Quality Palliative Care is to create a set of voluntary standards to guide the growth and development of palliative care in the United States.

Purpose of the Voluntary Consensus Standards for Quality Palliative Care

The focus of this document is on the specialist component of palliative care; future documents will address the need for standards of practice for palliative care in primary treatment settings.

TEXTBOX

The purposes of these Voluntary Consensus Standards for Quality Palliative care are to:

1. Facilitate the development and continuing improvement of clinical palliative care programs providing care to patients and families with life-threatening illness, particularly in institutions where a high proportion of people with acute and chronically progressive conditions are treated and ultimately die;
2. Establish uniformly accepted definitions of the essential elements in specialist palliative care that promote quality, consistency, and reliability of these services, and;
3. Foster continuity of palliative care by expansion of access to case management across settings, through hospice and other programs for patients with life threatening illness, and their families.

END TEXT BOX

The success of this project will be determined by the degree to which the National Voluntary Consensus Standards for Quality Palliative Care are used to: a) stimulate and guide the development and assessment of new and existing programs within and across care settings; b) ensure that palliative care programs deliver care of measurably high quality; c) promote formal recognition of specialty status for certification and accreditation initiatives in palliative care; and d) support the expansion of hospices' palliative case management and services in order to most effectively respond to the unparalleled volume of need in the near future.

[TEXTBOX or SIDEBAR]

Voluntary Consensus Standards for Specialist Palliative Care Programs: Baseline Assumptions

The following assumptions are fundamental to the development of the Voluntary Consensus Standards for Quality Palliative Care:

- Goal standards: These palliative care standards represent goals which palliative care programs should strive to attain, as opposed to minimal or lowest acceptable standards.

- Quality standards: These palliative care standards assume health care quality standards such as safety, leadership, medical record, and error reduction. . (Field & Cassel, 2001; Lynn, Schuster, & Kabcenell, 2000).
- Codes of ethics: These standards assume adherence to established professional and organizational codes of ethics.
- Ongoing revision: Palliative care standards will evolve as professional practice and the health care system changes over time. These standards were written assuming an ongoing process of evaluation and revision of palliative care standards (Kuebler, Dahlin, et al., 1996; Jacox, Carr, Payne, et al., 1994; Grossman, Benedetti, et al., 1999; Glance, Osler, & Shinozaki, 1998; HPNA competencies).
- Peer-defined standards: These voluntary consensus standards were developed through a consensus process of a broad range of palliative care professionals, are not linked to regulatory or reimbursement criteria, and are not mandatory. However, they are written with the intent that they will be used to promote the development of highest quality clinical palliative care services across the healthcare continuum, and that they will have utility in the establishment of professional education, certification, licensure and accreditation requirements (Zuckerman, 1999).
- Specialty care: These standards assume provision of services by palliative care specialists within an interdisciplinary team whose work reflects substantial involvement in the care of patients with life-threatening illnesses and their families. Qualifications are determined by organizations granting professional credentials, accreditation, and experience. (Covinsky, Fuller, et al., 2000). (HPNA competencies; Role delineation study; von gunten on ABHPM certification)
- Continuing professional education: These standards assume on-going professional education by all disciplines in the knowledge, attitudes, and skills required to deliver quality palliative care across the domains established in this standards document.

END TEXTBOX or SIDEBAR

Voluntary Consensus Palliative Care Standards

Excellence in specialist-level palliative care requires expertise in the clinical management of problems in multiple domains, supported by an infrastructure that furthers the goals of care and supports practitioners. Seven domains (Structure and Process, Physical, Psychological, Social, Spiritual, Cultural, and Ethical/Legal) were identified as the framework for these standards. These domains were drawn from the work of the previously established Australian, Canadian, and NHPCO standards efforts (Appendix 1; Australia; Canada; NHPCO, 2002; Freeborne, Lynn, Desbiens, 2000). Recent revisions of the NHPCO Standards of Practice for Hospice Programs have been subject to expert review by the American Academy of Hospice and Palliative Medicine, The Hospice and Palliative Nurses Association, the National Council of Hospice Professionals, the Joint Commission on Accreditation of Health Care Organizations, the Health Care Financing Administration (now named the Center for Medicare and Medicaid Services), the Center to Improve Care of the Dying, the Community Health Accreditation Program, the Accreditation Commission for Home Care, and the Hospice Association of America, among others. The relevant NHPCO standards will be referenced along with outcomes research and expert opinion in the section ahead, titled Voluntary Consensus Palliative Care Standards.

Each domain is followed by specific consensus standards regarding professional behavior and service delivery. These are followed by suggested criteria for assessing whether or not the identified expectation has been met.

Domain 1: Structure and Processes of Care

Standard 1.1 The plan of care is based on a comprehensive interdisciplinary assessment of patient and family.

Criteria:

- Assessment and its documentation is interdisciplinary, coordinated, and avoids unnecessary repetition (Glass, Cluxton, & Rancour, 2001; NHPCO: CC 2.2; IDT 14, 14.1,14.2)
- The initial and subsequent assessments are carried out through patient and family interview, review of medical records, discussion with other providers, physical examination, and relevant laboratory and/or diagnostic tests or procedures. (Hazzard, Woolard, Regenstreif, 2001; NHPCO: Clinical Care and Services 1.2, 1.3, 3, 6; IDT 3.1).
- Assessment includes documentation of disease status; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; social, cultural spiritual, and advance care planning concerns and preferences. (NHPCO: Access, Rights and Ethics 3.3, 3.4; CCS 1.2, 1.3, 2.1, 3, 3.1- 3.3, 8, 10, 11, 13)

- Documentation of patient and family expectations, goals for care, understanding of the disease and prognosis, as well as preferences for the site of care and site of dying are assessed and documented (von Gunten, Ferris, Emanuel, 2000; Kristjanson, 2001; Norton & Talerico, 2000; NHPCO: ARE 3, 3.5, 8, 14, 14.1, 14.2).
- Initial and ongoing assessment data are reviewed on a regular basis (Morita, Tsundoa, Inoue, et al., 1999; NHPCO: CC 2.2, IDT 12, 12.1-12.4)
- Policies for prioritizing and responding to referrals in a timely manner are documented. (NHPCO: Coordination and Continuity of Care 2.1; Management of Information 1.1, 1.2)

Standard 1.2 The care plan is based on the identified and expressed needs of the patient and their family, and is regularly reviewed by the interdisciplinary team.

Criteria:

- The care plan is based upon an ongoing assessment, determined by goals set with patient and family, and with consideration of the benefit/burden ratio of potential interventions at critical decision points during the course of illness. (Allen, Haley et al 2002; Block 2000; Steinhauser et al 2000; NHPCO: CC 2.2, IDT 11.3)
- The care plan is developed through the input of patient, family, primary physician, and palliative care team (NHPCO: IDT 11.1)
- Care plan changes are based on the evolving needs of the patient and family over time, and incorporate the potential for multiple and shifting priorities in goals of care.
- (Given, Gwen, et al., 2001; O'Neill & Fallon, 1997; Kristjanson, 1997; Wrede-Seaman, 1999; NHPCO: CC 2.4; IDT 12, 12.2).
- The interdisciplinary team coordinates and communicates the palliative care plan when patients transfer to different care settings.
- The evolving care plan must be clearly documented over time. (NHPCO: CC 2.3; IDT 12.1, 12.4; MI 3.3)

1.3 An interdisciplinary team provides services to the patient and family, consistent with the care plan.

Criteria:

- Palliative care is delivered by an interdisciplinary team (NHPCO: Interdisciplinary Team 1)
- The interdisciplinary team includes professionals with education, experience, credentialing, and skill in the assessment of patients with life-threatening illnesses, progressive debility and/or injuries and their families. (NHPCO: IDT 1.1)
- The team includes specialist palliative care professionals with the appropriate education, credentialing, and experience, and ability to meet physical,

psychological, social, and spiritual needs of the patient and their family. Of particular importance is the hiring of physicians and nurses appropriately trained and ultimately certified in hospice and palliative care. (Krammer, Ring, et al., 2001; Ferrell, Juarez, et al., 1999; NHPCO IDT 1.1, 15; Human Resources 1, 1.3)).

- The patient and their family have access to palliative care expertise and staff 24-hours per day, 7-days per week (Lynn, Schuster, & Kabcenell, 2000; NHPCO: CC 1, 1.1-1.3, 1.5; Hospice Inpatient Facility Clinical Care and Services 2; Hospice Residential Care Facilities Clinical Care and Services 1, 1.1, 1.2, 2; Nursing Facility Access, Rights and Ethics 1, 1.1)
- The interdisciplinary team communicates regularly (at least weekly) to plan, review, and evaluate the care of patients and families. (NHPCO: IDT 12.1, 12.2, 15.5)
- The team meets regularly to discuss provision of quality care, including staffing, policies, and clinical practices. (NHPCO: IDT 15.5; HR 1.1)
- Service leadership has appropriate training, qualifications, and experience (Billings, Block, Finn, et al., 2002; Ferrell, Virani, & Grant, 1999; NHPCO: Leadership and Governance 8.2, 12; HR 9.2)

1.4 The interdisciplinary team may include appropriately trained volunteers.

Criteria:

- If volunteers participate, policies and procedures are in place to ensure the necessary education of volunteers, and to guide recruitment, screening, training, support, supervision, and performance evaluation. (NHPCO: HR 7, 7.1-7.5).
- Policies are in place to guide the utilization, work practices, and supervision of volunteers, and the responsibilities of the service to its volunteers (NHPCO: IDT 8, 8.1; HR 4.3, 5, 5.1-5.4, 7.4, 7.5, 9).
- Volunteers are screened, educated, coordinated and supervised by an appropriately trained professional team member. (NHPCO: HR 7.5)

1.5 Support for education and training is available to the interdisciplinary team, and other health professionals.

Criteria:

- Educational resources and continuing professional education are provided to staff (Christ & Sormanti, 1999; Miller, Hedlund, & Murphy, 1998; NHPCO: HR 3.5, 3.6, 4, 4.1-4.5, 5, 5.1- 5.4, 6, 6.1-6.3, 7, 7.1, 7.2, 9, 9.1, 9.2).

1.6 The palliative care team is committed to quality improvement in clinical and management practices.

Criteria:

- Quality improvement and research policies are established by the palliative care service (Lynn, 1997; Hearn & Higginson, 1997; Scanlon, 1997; NHPCO: Performance Improvement I 2, 2.1, 2.2).
- Quality improvement activities are routine, regular, reported, and are shown to influence clinical practice. (IHI cites; NHPCO: PI 2.3, 4.3)
- The clinical practices of palliative care program reflect the integration and dissemination of research and quality improvement evidence (Hermann & Looney, 2001; Teno et al., 1999; Smeenk et al., 1998; Donaldson & Field, 1998; NIH, 1997; NHPCO PI 6, 6.1, 6.2).
- Quality improvement for clinical services and research are collaborative, interdisciplinary, and focused on meeting the identified needs of patients and their families (Grant & Hanson, 2002; Lynn, 2000; Morrison, Siu, Leipzig, Cassel, & Meier, 2000; Du Pen, et al., 1999; ABIM, 1998; McGlynn, Cassel, et al., 2003; Last Acts, 2002; Teno et al., 2000; NHO, 1997; United Hospital Fund, 1998; ABIM, 1998: Rudberg, Teno, & Lynn, 1997; American Pain Society Quality of Care Committee, 1995; McCarthy & Higginson, 1991; PI 1.1, 2.2, 3.2).
- Patients, families, health professionals, and the community may provide input for evaluation of the service (Reese, Raymer, & Richardson, 2000; Singer, Martin, & Kelner, 1999; Skolnick, 1998; McWhinney, Bass, & Donner, 1994; NHPCO: PI 3.2, 4, 4.1).
- An appropriate institutional review board oversees and guides all research initiatives.

1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families.

Criteria:

- Situational support is available to staff and volunteers (NHPCO: HR 4.5).
- Policies guide the support of staff and volunteers, including regular meetings for review and discussion of the impact and processes of providing palliative care. (NHPCO: HR 4.4, 4.5)

1.8 Palliative care programs should have a relationship with one or more hospices to ensure continuity and highest quality palliative care across the illness trajectory.

Criteria:

- When appropriate, patients and families are routinely informed about hospice at the time of referral to the palliative care program.

- Referring physicians and health care providers are routinely informed about the availability and benefits of hospice for their patients and families as appropriate and indicated. (NHPCO: ARE 1.4)
- Policies for formal written and verbal communication about all domains in the plan of care are established between the palliative care program and the hospice program.
- Where possible, hospice and palliative care program staff routinely participate in each others' team meetings to promote regular professional communication, collaboration and partnership on behalf of patients and families.
- Palliative and hospice care programs routinely seek opportunities to collaborate and work in partnership to promote increased access to quality palliative care across the continuum (Meier 2002).

Domain 2: Physical

2.1 Pain and other symptoms, and treatment side effects are managed based upon the best available evidence, which is skillfully and systematically applied.

Criteria:

- The interdisciplinary team includes professionals with specialist-level skill in symptom control (Miller et al., 1998; Glass, et al., 2001; NHPCO: IDT 1.1; HR 4, 4.1, 4.2, 4.4).
- Regular, ongoing assessment of pain, non pain symptoms, treatment side effects and function occurs, and is documented. (Buckman, 1998; Ramirez, 1998; Lynn, Teno, et al., 1997; NHPCO: CCS 1, 1.2, 1.3, 2, 2.1, 2.5, 3, 3.1, 3.2, 10, 14; IDT 11.2, 12, 12.1, 12.2, 12.3, 12.4; MI 3.3).
- Assessment includes patient/family understanding of disease, symptoms, side effects, functional impairment, and their treatments, as well as their caregiving capacity and coping strategies with these issues. (NHPCO: IDT 5.1, CCS 6, 11, 13, 13.1, 13.2, 14, 14.1, 14.2)
- Assessment is coordinated to reduce repetition (Pasacreta, Minarik, & Nield-Anderson, 2001).(Meier, 2002; Glass, Cluxton, & Rancour, 2001; NHPCO: CC 2, 2.1-2.5)
- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences. Re-evaluation of treatment efficacy and patient-family preferences is documented (Block, 2000; Larson & Tobin, 2000; Bruera & Fainsinger, 1998; Mannix, 1998; Baines, 1997; NHPCO: CCS 1, 2, 2.2, 4.2; IDT: 11.3, 13.2, 15.2, 15.3).
- Treatment of distressing symptoms and side effects incorporates pharmacological, non pharmacological, and supportive therapies.
- Referrals to healthcare professionals with specialized skills in symptom management are made available when appropriate (eg, radiation therapists;

anesthesia pain experts, orthopedists, physical therapists) (NHPCO: CCS 5.4; IDT 6).

- Response to symptom distress is prompt and tracked, through documentation in the medical record. (Bruera, MacEachern, et al., 1993; DuPen, 1999; NHPCO CC1.1, 2; IDT 13.3).
- Treatment alternatives are clearly documented and communicated and permit the patient and their family to make informed choices (Mariano, 2001; NHPCO, 2001; Corner, et al., 1996; NHPCO: ARE 3, 3.1, 3.5)
- Family is educated and supported to provide safe and appropriate comfort measures to the patient (Perrin, 2001; Lo, 2000(NHPCO: CCS 3.3, 13, 13.1, 13.2, 14, 14.1, 14.2; IDT 4.1, 5.1; HR 7.2).
- A process for quality improvement and review of physical and functional assessment and effectiveness of treatment is documented and leads to change in clinical practice. (NHPCO : PI 4, 4.1, 4.3, 4.4, 5.2, 6).

2.2 The imminence of death is recognized, and care appropriate for this phase of illness is provided to patient and family.

Criteria:

- The patient's and family's transition to actively dying phase is recognized, documented and communicated appropriately to patient, family, and staff. (Kristjanson, 2001; Zabora & Loscalzo, 1998).
- As patients decline, the hospice referral option will be reintroduced for those who have not yet accessed hospice services.
- The care plan is revised (Lo, 1996) to meet the unique needs of the patient and their family at this phase of their illness. The need for higher intensity and acuity of care during the active dying phase is met and documented . (NHPCO: CCS 1-15; Fine, 1998; NHPCO: CCS 15.1).
- Patient and family wishes regarding care setting for the death are documented. Any inability to meet these needs is reviewed and addressed by the palliative care team (Lo, 2000; Kristjanson, 1997; NHPCO: CCS 6, 13; CC 3, 3.1,3.2).
- End of life concerns, fears, and expectations are addressed openly and honestly in the context of social and cultural customs (Perrin, 2001; Lo, Quill, & Tulsky, 1999; Monroe, 1998; Corr, 1998; NHPCO: CCS 9, 9.3, 12).
- Symptoms at the end of life are assessed and documented frequently and are treated based on patient preferences (Abrahm, 2000; Du Pen et al., 1999; Bruera, 1997; NHPCO: CCS 2, 3).
- The family is educated regarding the physical and emotional processes of dying. (Sherman, 2001; Coyle et al., 1999; NHO, 1996; Pickett & Yancey, 1998). (NHPCO: CCS 12.3)
- Emotional and spiritual support for the patient and family is provided during the dying process and bereavement period (Novak, 2001; Levine, 2000). (NHPCO: CCS 7, 7.1, 7.2; CCS 11, 11.1-11.3; Bereavement Care and Services 2, 3.)

- Appropriate and sensitive care to patient and family occurs in the hours following death including physical care of the body in accordance with spiritual needs, cultural expectations, and rituals (Berry & Griffie, 2001; Matzo, 2001; Kristjanson, 1997; NHPCO: CCS 15.4; HIFCCS 5, 5.1; HRCFCCS 5, 5.1)).
- Staff are trained in the pronouncement of death; completion of the death certificate; organ and tissue donation; and offer of an autopsy (NHPCO: CCS 15.3).
- Families are offered guidance and information regarding funeral arrangements. (NHPCO: CC 2.6)

2.3 The importance of the physical environment in which care is provided is recognized.

Criteria:

- When feasible, care is provided in the setting preferred by the patient and their family (von Gunten, 2002; Emanuel, 2000; Lo, 2000; Lo, 1996; NHPCO: ARE 3.5; CCS 10.2, 13.2, 14; CC 3.1-3.4; HIFARE 1.1).
- The care setting addresses safety, space for families to visit, rest, eat or prepare meals, meet with the palliative care team, flexible visiting hours, and privacy. (NHPCO: HIFCCS 3; HIFSIC 1,1.1-1.7, 5; HRCFSIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4).

Domain 3: Psychological

3.1 Psychological impact of illness on patient and family is assessed and addressed.

Criteria:

- Stress or grief-related disorders, coping strategies, adjustment of patient and family, and other psychiatric conditions are formally and regularly assessed and reviewed. (Buckman, 1998; Ramirez, 1998; Lynn, Teno, et al., 1997; NHPCO: IDT 5.1; CCS 6, 6.1-6.3, CCS 11, 11.1-11.3; . (NHPCO: CCS 6, 6.1-6.3, 7, 7.1))
- The interdisciplinary team includes professionals with skill in psychological assessment and care during a life-threatening illness (Miller et al., 1998; Glass, et al., 2001; NHPCO: IDT 1.1).
- Psychological support is provided to the patient and family by members of the interdisciplinary team. The goal is to address psychological needs, promote adjustment, and support opportunities for emotional growth, healing, reframing, completion of unfinished business, and support through the bereavement period (Pasacreta et al., 2001; Kuebler et al., 2001; Steinhauser, Christakis, et al., 2000; Massie & Payne, 1999; Chochinov et al., 1998; Lynn et al., 1997; Lo, Quill, & Tulsky, 1999; Kristjanson, 1997; Quill, 2000; Lo, Snyder, & Sox, 1999; NHPCO: IDT 5 .1; CCS 7, 7.1, 7.2, 9, 9.1-9.3, 11, 11.1-11.3 12, 12.1-12.4, 2.6.).

- Identified psychiatric co-morbidities in patient and family are treated or referred for treatment.

3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services.

Criteria:

- Grief and bereavement risk assessment is routine and ongoing for the patient and their family throughout the illness trajectory, recognizing issues of loss and grief in living with a life-threatening illness (Corless, 2001; NHPCO: BCS 2, 2.2, 2.3).
- Clinical assessment is used to identify people at risk of complicated grief and bereavement (Potter, 2001; NHPCO: BCS 2.1, 3.4).
- Information on loss and grief and the availability of bereavement support services are made routinely available to families before and after the death of the patient. (Brown-Saltzman, 1998; Stanley, 2000; NHPCO: IDT 5.1, 6.3, 3.3).
- Support and grief interventions are provided in accordance with developmental, cultural, and spiritual needs, expectations and preferences. (Rando, Speck, Murray-Parkes; NHPCO: BCS 2, 2.1-2.3)
- Staff and volunteers who provide bereavement services receive ongoing education, supervision, and support (Saunderson, Ridsdale, Jewell, 1999; NHPCO: BCS 4, 4.1, 4.2).
- Bereavement services are recognized and funded as a core component of the palliative care service (Potter, 2001; NHPCO: IDT 1.1).'
- Bereavement services and follow-up are made available to the family for at least 12 months after the death of the patient. (NHPCO: BCS 1)

Domain 4: Social

4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families.

Criteria:

- The interdisciplinary team includes professionals with skills in the assessment and management of social and practical needs during a life-threatening illness. (NHPCO: IDT 1.1)
- A comprehensive interdisciplinary social assessment is completed and documented, to include: family structure; relationships; lines of communication; existing social network; perceived social support; medical decision making; work settings; finances; sexuality; intimacy; living arrangements; caregiver availability; access to transportation; access to prescription and over- the-counter medicines; access to needed equipment; community resources; and legal issues (Crawley, Payne, et al., 2000; Borum, Lynn, & Zhong, 2000; Burrs, 1995; NHPCO: IDT 5.1; CCS 6, 6.1-6.3; 7, 7.1, 7.2, 11, 14, 14.1, 14.2).
- The social care plan is formulated from a comprehensive social and cultural assessment and re-assessment, and reflects and documents values, goals, and

preferences set by patient and family over time (Hopp & Duffy, 2000; Keovilay, Rasbridge, Kemp, 2000; Koenig & Gates-Williams, 1995; Waters, 2000; Loudon, Anderson, et al, 1999; Morrison, Zayas, Mulvihill, Baskin, Meier, 1998; NHPCO: IDT 5.1, 11, 11.1-11.3; CCS 6, 6.1-6.3, 7, 7.1, 7.2, 9, 9.1-9.3, 12, 12.1-12.4)

- Family meetings are routine and are conducted with members of the interdisciplinary team to assess understanding and address questions, provide information, discuss goals of care and advance care planning, determine wishes and preferences, provide emotional and social support, and enhance communication (Larson & Tobin, 2000; Ambuel, 1999; Davis, 1996; Eleazer, Hornung, et al., 1996; Hopp, 2000; Hallenbeck & Mebane, 1996).

4.2 An individualized and comprehensive care plan addressing social and cultural needs is developed in consultation with patient and family.

Criteria:

- Interventions are planned to alleviate caregiver burden and promote caregiver goals and well-being (Sulmasy, 1997; NHPCO: CCS 10, 10.1-10.3, 11, 11.1, 11.3, 13, 13.1, 13.2).
- Referrals to appropriate services are made to meet identified social needs and which promote access to care, help in the home, transportation, rehabilitation, medications, community resources, and equipment. (NHPCO: IDT 6, 6.3; CCS 14, 14.1, 14.2)

Domain 5: Spiritual or Existential

5.1 Spiritual concerns are assessed.

Criteria:

- The interdisciplinary team includes professionals with skills in the assessment of and response to spiritual needs associated with life threatening illness (NHPCO: IDT 1.1)
- A spiritual assessment is utilized to identify religious background, spiritual preferences, and related beliefs and practices of the patient and family (O'Connor, 1993; NHPCO: IDT 7, 7.1, 11, 11.2).

5.2 Religious beliefs of patient and family are recognized and respected and spiritual and religious support is provided for patients and their families as appropriate.

Criteria:

- The interdisciplinary team includes members of the clergy or chaplains. (NHPCO: IDT 1.1; HIFCCS 2, 2.1, HRCFCCS 2, 2.1.

- Spiritual care needs are addressed, documented, and incorporated into the plan of care developed with the interdisciplinary team, patient, and family (Spross, 1996; Highfield, 2000; Sherman, 2001; NHCPO: IDT 7, 7.1, 11.1).
- Pastoral care professionals facilitate contacts with the community and spiritual/religious groups or individuals, as desired by the patient and/or family (Speck, 1998; NHPCO: IDT 7.1).
- Patients have access to clergy in their own religious traditions.
- (NHPCO: IDT 7.1; HRCFCCS 2 practice example)
- There is sensitive use of professional and institutional religious symbols and icons
- The patient and their family are encouraged to display their own religious/spiritual symbols and icons.
- The palliative care service facilitates religious rites and rituals as desired by patient and family (HRCFCCS 2, 5.2).

Domain 6: Cultural

6.1 The palliative care service assesses and aims to meet the culture-specific needs of the patient and family.

Criteria:

- The cultural background, concerns, and needs of the patient and their family are assessed and documented. (Kagawa-Singer, 1998; Bates & Sanchez-Ayendez, 1997; NHPCO: CCS 6.1; 11.1, 11.2, 12.4; IDT 4.1.9, 5.1, 7.3).
- Cultural needs are identified in the interdisciplinary team care plan. (Waters, 2000; ONS, 1999; Taylor & Box, 1999; Koenig, 1997; Koenig, & Gates-Williams, 1995; NHPCO: IDT 4, 4.1.9, 5, 5.1.10, -7, 7.1.3.).
- The program aims to respect and accommodate the range of language, dietary, habitual, and ritual practices of the patients and their families (Mitty, 2001; Mariano, 2001; Zoucha, 2000; Hallenbeck, 1999; NHPCO: ARE 2, 2.1, 2.2).
- The team has access to and utilizes appropriate translation resources (Solomon, 2000; Langford, 2000; Kagawa-Singer, 1996).
- Recruitment and hiring practices strive to reflect the cultural diversity of the community. (NHPCO: HR 8, 8.1, 8.2)

Domain 7: Ethics and Law

7.1 The patient's goals, preferences and choices are respected and form the basis for the plan of care

Criteria:

- The patient's expressed wishes, in collaboration with the family and the interdisciplinary team, form the basis for the care plan. (NHPCO: ARE 3, 3.5; IDT 11)

- The palliative care program promotes advance care planning in order to understand and communicate patient's preferences for care across the healthcare continuum. (Wenger et al., 2000; Hammes & Rooney, 1998; Bradley, Peiris, & Wetle, 1998; Miles, Koe, & Weber, 1996; NHPCO: ARE 3.3, 3.4).
- When patients are unable to communicate, the palliative care program seeks to identify advance care directives, evidence of previously expressed wishes, values and preferences, and the appropriate surrogate decision-makers (NHPCO: ARE 3.2, 3.3, 6.2.
- Evidence of patient preferences for care is routinely documented in the medical record. (NHPCO: ARE 3.2, 3.3, 3.5, 3.6)

7.2 The palliative care service is aware of and addresses the complex ethical issues arising in the care of persons with life threatening illness.

Criteria:

- Ethical concerns commonly encountered in palliative care are recognized and addressed, using ethical principles to prevent or resolve ethical dilemmas, including: beneficence; respect for persons and self-determination and associated regulatory requirements for truth-telling, capacity assessment, confidentiality, and informed consent; attention to justice and to nonmalificence and associated avoidance of conflicts of interest. (Schwarz, 2001; Mezey et al., 2000; Scanlon, 1998; Scanlin & Rushton, 1998; Blackhall, Murphy, et al., 1995; NHPCO: ARE 8, 8.1, 8.2).
- Care is consistent with the professional codes of ethics, and scope, standards, and code of ethics of palliative care practice are modeled on existing professional.codes of ethics for all relevant disciplines. (Appendix 1; NHPCO re 8, 8.1, 8.2; (NHPCO: IDT 15.1cite codes of ethics for all relevant disciplines and palliative care professional organizations).
- The palliative care team aims to prevent, identify, and resolve ethical dilemmas related to specific interventions such as withholding or withdrawing treatments (including nutrition and hydration), instituting DNR orders, the principle of double effect, and the use of sedation in palliative care (Stanley, & Zoloth-Dorfman, 2001; Faber-Langerhorn, 2000; Hamel et al., 1999; Roy & MacDonald, 1998; Faber-Langerhorn, 1996).
- Ethical issues are documented; referrals are made to ethics consultants or committee, as appropriate (Jurchak, 2000; Dowdy, Robertson, & Bander, 1998; NHPCO: ARE 8, practice example.).

7.3 The palliative care service is knowledgeable about legal and regulatory issues related to palliative care.

Criteria:

- Palliative care practitioners are knowledgeable about legal and regulatory issues, including federal and state statues and regulations regarding medical decision-making, advance care planning and directives, the roles and responsibilities of surrogate decision-makers; appropriate prescribing of opioids and other controlled substances; pronouncing death; request for autopsy and organ transplant; and associated documentation in the medical record (Ramsey, 2001; Midwest Bioethics Center, 2001; Thorns & Sykes, 2000; Mezey et al., 2000; NHPCO: ARE 6.2; CCS 14.1, 14.2).

Conclusion

Palliative care programs aim to support patients and families through the course of illness and bereavement through skilled, interdisciplinary attention to pain and symptom distress, emotional, spiritual, and practical support, and coordination across the continuum of healthcare settings. The goal is to achieve the best possible quality of life as determined by the patient and their family. These standards for quality palliative care programs represent the consensus opinion of the major palliative care organizations and leaders in the United States, and are based both on scientific evidence and expert professional opinion. Standards are required to encourage a level of consistency, comprehensiveness, and quality that patients and families can come to expect and rely upon, whatever their diagnosis, wherever they live, and regardless of the setting of care. The widespread adoption of these standards in the United States will promote access to consistent and high quality clinical services and establish palliative care standards as the expectation for the health care of persons living with life threatening illness.

APPENDIX 1

Palliative Care and the Hospice Movement in the United States

While new clinical specialties in palliative medicine and nursing are emerging, palliative care is not new. At 30 years of age, it is older than personal computers, in vivo magnetic resonance imaging and HIV/AIDS. Richard Nixon was president when the first palliative care program, The Connecticut Hospice, was inaugurated in the United States in 1974. Early standards for hospice, developed 4 years before the advent of the Medicare Hospice Benefit, clearly state a philosophy that is relevant to hospices' expansion of palliative care services today:

> "Appropriate therapy is the goal of Hospice Care....Appropriate medical care is always a blend of two complementary systems of therapy—curative and palliative...Even if (curative therapies) do not produce a cure, they may still be partially successful in establishing disease control....Seldom does a patient receive therapy that is solely curative or palliative in nature. Rather there is an equilibrium between these two systems of therapy from the time of diagnosis until the time of death." (National Hospice Organization, 1979, p. 10)

Surveys in the United States have consistently demonstrated a high rate of satisfaction among Americans with hospice services, which is reimbursable under the Medicare (1983) and Medicaid programs, as well as most private insurance carriers. Hospice programs created increased opportunity for death at home, focusing on symptom control and psychological and spiritual issues that has been lacking in other health care contexts. Since 1974 over 7 million patients and their families have received high quality end-of-life care at home (e.g. a private residence, assisted living facility, group home, homeless shelter) as well as in nursing homes and hospitals through certified hospice programs. (NHPCO, 2003).

The primary clinical characteristics of hospice care and palliative care are inclusive. Both palliative care and hospice programs:

- Acknowledge the patient and their family as the unit of care, and value reduction of caregiver mortality and morbidity by actively reducing the physical and emotional burden associated with caregiving and grief.
- Rely on interdisciplinary assessment, treatment and evaluation.
- Energetically respond to the consequences of illness facing the patient and family, including:
    - The need for symptom management
    - Practical guidance and support of care at home, where most people spend most of their time and most prefer to be as death approaches.
    - Anticipatory counseling/crisis prevention/critical decision support.
    - Health promotion, even in the face of physical decline.

- Address historic forms of patient abandonment, such as the health care workers' isolation of patients who "failed therapy," believing "nothing more can be done."
- Incorporate a human development perspective with respect to life-altering illness.

Responding to Community Need:

Since the mid 80's leading hospices have aimed to expand access to services in order to reach people based on human need, even if these individuals did not meet prognostic requirements or were unwilling to give up disease-modifying care. This effort has grown, despite the increasingly strict eligibility requirements imposed by hospices' fiscal intermediaries.. Some hospices, such as Hospice of Michigan, San Diego Hospice and Palliative Care, and Hospice and Palliative Care of the Bluegrass have contributed to palliative care education through relationships with local universities and colleges in schools of medicine, nursing, pastoral care, and social work. Hospice programs that provide services outside of conventional hospice benefits, are referred to as "upstream hospice," while those with dedicated professional education, research and public policy/advocacy components are referred to as "comprehensive hospice centers." (Jennings et. al. 2003, pp48-49.).

In the past 8-10 years, physicians, nurses and other health care professionals in universities and teaching institutions have championed efforts to improve care for those seriously ill patients that hospices have traditionally not served. These services, while variably defined, have been collectively termed "palliative care programs." They may be independent of hospice services or contractually related to hospices. In some hospitals, such as UCSF Medical Center, "comfort suite" services are offered for dying patients who are unlikely to leave the hospital. In other hospitals, such as the Ireland Cancer Center at Case Western Reserve University School of Medicine in Cleveland, palliative care clinicians provide intensive symptom management and counseling to patients and family members from the point of diagnosis and throughout the course of cancer treatment. In still other models, the palliative care program staff work in close collaboration with local hospice staff to ensure continuity of care when a patient is discharged home or to a nursing home.

TEXT BOX

Hospice Utilization and Growth.

Not all Americans who die each year are "patients." The National Hospice and Palliative Care Organization estimates those who would benefit from hospice care are approximately 70% of the total number of Americans who die. Death from homicides, suicides, drug and alcohol use, unintentional injuries (fires, drowning, suffocation, poisonings, motor vehicle accidents, falls, etc.) or sudden death events from disease (MI, stroke, hemorrhage, infection, etc.) would not be part of the hospice or palliative care denominator.

It is estimated that hospices provide care to 40% of Americans who experience a death with a preceding period of dependency in activities of daily living (www.nhpco.org), and in 2002 50% of US hospice patients had noncancer diagnoses. Currently, more than half of the patients in the US who die with a diagnosis of cancer opt for hospice care, while in an increasing number of hospices care for over 90% of patients with cancer in their communities.

It is conservatively estimated that an additional two million caregivers received family/bereavement services in 2002. (www.nhpco.org, 2003).

Until recently, the epidemiologic consequences of hospice programs bereavement service requirement have been unrealized. In a matched cohort study of 195,553 elderly spouses of hospice and nonhospice decedents, Medicare claims data demonstrates a statistically significant positive difference in survival rates for the spouses of hospice decedents, particularly among wives. (Christakis and Iwashyna, 2003.)

END TEXT BOX

The relevant differences between hospice programs and palliative care programs are summarized in Table 1. Their synergistic potential is based on their complementary core competencies and practice patterns. This potential is important, for hospice expansion *and* improvement in the delivery of palliative care in settings such as hospitals have, together, the capacity to respond to the needs of the growing population of elderly with chronic and serious illness.

TABLE 1.

Current Similarities and Differences between Hospice and Hospital Based Palliative Care Programs

	Hospice	Hospital based PC
Informed Consent?	Patient signs informed consent for hospice services and care management across settings	Patient signs informed consent for hospital services and risk-bearing therapies
Prognosis Requirement?	Medicare requires a 6 month prognosis and state licensure requirements vary from 6 months to a "limited life expectancy." Individual hospices may serve patients > 6 months.	No
Curative Treatment Restrictions?	Frequently	No
Life-prolonging Treatment Restrictions?	Program specific. Some palliative treatments may extend life	No Some palliative treatments may extend life
Use of "high tech/high cost" treatments for symptom management (radiation therapy, chemotherapies, blood products)	Variable, dependent on factors such as hospice size and resources and proximity to delivery site	Available
Average and Median Length of Stay	2001: ALOS 48 days MLOS 20.5 Can repeat admissions	Data not available, presumed to be variable Can repeat admissions
Range in length of service	Generally hours to months, though x% of patients enrolled on the MHB are alive at the end of 1 year.	Hours to years

Pt/family focus?	Yes	Yes
IDT?	Defined by NHPCO Standards of Practice for Hospice Programs and regulated through accreditation standards, state licensure and Medicare Conditions of Participation	Variably defined and unregulated
24/7 case mgt across settings?	On-call coverage 24/7 in unregulated home environments and other care sites for phone advice and emergency visits	Intensive 24/7 coverage in highly regulated environment MD or NP is most often the "case manager" available by phone for crises outside of hospital.
Primary treatment setting	Home	Hospital
Provides routine and direct care to persons in nursing homes?	Yes Nursing homes considered primary residence	Generally not
Provides and supervises care at home?	Yes	Generally not, except in association with hospice or home health program
Bereavement services	Yes	Variable
Community engagement on issues of grief and loss	Yes	Variable
<u>Program regulation</u>: **JCAHO Accreditation** **Medicare Certification** **State Licensure**	Yes, mandatory in programs that have an accredited parent, such as hospitals Yes 46/50 states	Palliative care is not currently regulated but most often provided in accredited hospitals and state licensed nursing homes.

Primary form of reimbursement	Medicare/Medicaid/private insurance	Medicare Part B/DRG Medicaid/private insurance
Voluntary Consensus Standards	Original: 1979 Revised 1983, 1987, 1993, 2000	2003 proposed

The rationale for the palliative care - hospice continuum is apparent: the hospice community has been instrumental in the growth of palliative care, as it has continuously sought and found better ways to serve patients and families. As of 2002, 41% of hospices are delivering palliative care services outside of the Medicare Hospice Benefit, and another 19% are planning such programs (NHPCO, Connor, 2003). Importantly, nearly a third of the nation's 3,200 hospices are hospital based, and many hospital, nursing home, and home care agency palliative care programs have been both initiated and supported by hospice professionals. Further, all reported data to date suggest that palliative care programs in a range of care settings (cites Ireland Cancer center, Mt Sinai, Kaiser, others) result in marked increases in number of appropriate referrals and length of stay in hospice.

As a philosophy of care, the palliative care services and case management offered by hospices should be available to any patient and family who can benefit. Access to hospice programs should not be influenced by the availability of life prolonging therapies or the patient's desire to pursue these approaches, for many patients wish to continue life prolonging treatments as long as the treatment benefits outweigh the burdens

Finally, while this document has largely focused on the development of standards that have a high degree of applicability in hospitals, focused efforts need to be made to improve the quality of life and life closure of Americans in nursing homes, where limited resources and staff turnover often make the availability of expert interdisciplinary palliative care services difficult. (Miller, 2000, pg. 11) In partnership with hospitals and other community partners, palliative care programs and hospices must consider how best to extend palliative services to this vulnerable population.

History of the National Consensus Project

Development of U.S. palliative care consensus standards was discussed during a national leadership conference coordinated by the Center to Advance Palliative Care (CAPC) held in December, 2001, at the New York Academy of Medicine. Participants at this conference (listed at www.nationalconsensusproject.org) were identified through a national peer nomination process. The early goals of the National Consensus Project were:

1. To define an effective national consensus process for establishment of voluntary consensus standards for quality palliative care in the United States;

2. To develop such standards through an evidence-based iterative review process that involved the major palliative care organizations in the United States and a large number of professionals in diverse disciplines; and

3. To disseminate these standards to all stakeholders involved in the delivery of healthcare to persons with life-threatening illnesses in the United States.

A timeline detailing the activities of the National Consensus Project between December 2001 and the standards publication date may be found on page X.

Organizational Structure of the National Consensus Project

The National Consensus Project has been structured to maximize the participation and input of a broad range of palliative care professionals, healthcare organizations, policy and standard-setting bodies, consumers, and payers. To this end, a series of working groups has been formed to ensure a comprehensive, transparent, and representative consensus process underpinning the development of Voluntary Consensus Standards for palliative care.

Consortium Organizations for the NCP: Based on recommendations from the broader palliative care community, five key national palliative care organizations formed a consortium to oversee and ensure the success of the National Consensus Project. The Consortium includes:

- **American Academy of Hospice and Palliative Medicine:** A physician membership organization for palliative care and hospice professionals.
- **Center to Advance Palliative Care:** A Robert Wood Johnson Foundation–funded initiative to promote the development of quality palliative care programs in hospitals and other healthcare settings.
- **Hospice and Palliative Nurses Association:** A nursing membership organization for palliative care and hospice professionals.
- **National Hospice and Palliative Care Organization:** A hospice membership organization serving U.S. hospices.
- **Partnership for Caring: America's Voices for the Dying:** A membership organization for consumers and other constituencies promoting patient rights in healthcare decision-making and access to care.

Steering Committee: Each of the five consortium organizations has appointed 4 representatives to a Steering Committee (members listed on page _____). The Steering Committee is charged with the responsibility for ensuring the timely completion of the consensus document, communication and dissemination of progress reports to all appropriate stakeholders, and procurement of the necessary financial support for the project. The Steering Committee has made all decisions regarding the NCP through a voting process at regular monthly meetings.

Advisory Committee: An Advisory Committee (list of members in Appendix) was established concurrent with the Steering Committee. This group, which includes approximately 100 nationally recognized palliative care leaders nominated by their peers, has served as document reviewers and key contributors to document development and revision.

Liaison Organizations: During the process of document creation, a list of potential Liaison Organizations was developed (list of organizations in Appendix). Approximately 50 organizations with major responsibility for healthcare of patients with life-threatening illnesses in the U.S. have been invited to offer their endorsement and to assist in broadest possible national dissemination of the standards.

Process for Developing Consensus

The Steering Committee developed a process for drafting and reviewing the document. The steps in this process are as follows:

- An outline that identified the key domains to be addressed was developed by the Steering Committee after review of all existing standards and consensus documents (Appendix 1), and input from the Advisory Committee.
- Voluntary standards were developed based on consensus and the best available medical evidence.
- Drafts of the document were reviewed and edited by the Steering Committee.
- Using a 1 - 4 scale, the Steering Committee reviewed and rated each section/item. A score of 1 was a full rejection; a 2 was a rejection with multiple reservations; 3 indicated acceptance with reservations and 4 indicated full acceptance of the section/item.
- A tally of the total Steering Committee ratings and comments were reviewed and discussed with resolution and/or revision of any item receiving less than 70% agreement.
- The revised document was reviewed by the Steering Committee. When the vote on acceptance of the entire document achieved greater than 70% agreement, the document was then distributed to the Advisory Committee (members listed in Appendix 2) for review and rating using the 1-4 scale, and to the five Consortium Organizations for review by their Boards of Directors or respective governing bodies.
- Feedback and ratings by the Advisory Committee and Consortium Organization Boards were tallied and reviewed by the Steering Committee. Subsequent revisions were reviewed, voted on, and approved by the Steering Committee. Unanimity of approval by the five consortium organizations was required at this stage of document development.
- The document was then distributed to approximately 50 Liaison Organizations with major responsibility for healthcare of patients with life-threatening illnesses in the U.S. for possible endorsement and assistance in national dissemination of the standards.
- In order to ensure the success and effectiveness of the project in improving access to quality palliative care in the United States, a comprehensive communication

and dissemination plan for the document was developed. The communications plan will ensure distribution of the standards to organizations, associations, clinicians, managers, providers, policy makers, educators, researchers, and other individuals planning, providing, or assessing palliative care programs.

DO NOT RATE BEYOND THIS POINT

Financial support has been provided by the following organizations:

American Academy of Hospice and Palliative Medicine
Center to Advance Palliative Care
The Charitable Leadership Foundation
Hospice of the Western Reserve
Hospice and Palliative Care Nurses Association
The Mayday Fund
National Hospice and Palliative Care Organization
Partnership for Caring: America's Voices for the Dying
Purdue Pharma Fund

In-kind support has been provided by the following organizations:
The National Hospice Work Group

Appendix 2:

Resource Materials

American Association of Colleges of Nurses. (1997). *A Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Care*. [Report from the Robert Wood Johnson End-of-Life Care Roundtable]. Washington, DC: Author.

American Association of Critical-Care Nurses. (1999). *Designing an Agenda for the Nursing Profession on End-of-Life Care*. [Report of the Nursing Leadership Consortium on End-of-Life Care]. Washington, DC: Author.

American Nurses Association. (1991). *Position statements: Promotion of comfort and relief of pain in dying patients.* Washington, DC: Author. Retrieved from http://www.ana.org

American Board of Internal Medicine. (1996). Caring for the Dying, Identification and promotion of Physician Competency, Philadelphia, PA: Author.

American Nurses Association. (1991). *Position statements: Assisted suicide and euthanasia.* Washington, DC: Author. Retrieved from http://www.ana.org

American Nurses Association. (1991). *Position statements: Nursing and the patient self-determination acts.* Washington, DC: Author. Retrieved from http://www.ana.org

American Nurses Association. (1991). *Position statements: Nursing care and Do-Not-Resuscitate decisions.* Washington, DC: Author. Retrieved from http://www.ana.org

American Nurses Association. (1991). *Foregoing nutrition and hydration.* Washington, DC: Author. Retrieved from http://www.ana.org

American Geriatrics Society. (1996). Measuring quality of care at end-of-life: A statement of principles. NY: NY: Author. (online) Available: http://www.americangeriatrics.org (March 5, 2000).

American Medical Directors Association. (2000). *White paper on hospice in long term care.* Columbia, MD: American Medical Directors Association.

Centers for Medicare and Medicaid Services. Conditions of Participation for Hospice http://www.access.gpo.gov/nara/cfr/waisidx_01/42cfr418_01.html

Clinical Standards Board for Scotland Clinical Standards for Specialist Palliative Care. CSBS, June 2002. www.clinicalstandards.org

Emanuel, L. L., von Gunten, C. F., & Ferris, F. D. (Eds.). (1999). *The EPEC Curriculum: Education for Physicians on End-of-life Care*. The EPEC Project. Retrieved from http://www.EPEC.net

Ferrell, B. R., Grant, M., & Virani, R. (1999). *End-of-Life Care Content Guidelines*, Duarte, CA City of Hope. Distributed via City of Hope Pain/Palliative Care Resource Center. Can be found at http://prc.coh.org/default.asp

Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syne A, West P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching Death: Improving Care at the End-of-Life* (Report of the Institute of Medicine Task Force). Washington, D.C.: National Academy Press.

Grossman, S. A., Benedetti, C., Payne, R., & Syrjala, K. (1999). NCNN practice guidelines for cancer pain. *Oncology, 13*, 33-44.

Hastings Center. (1987). *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying.* Bloomington, IN: University Press.

Hospice and Palliative Care Nurses Association. (2000). *Statement on the Scope and Standards of Hospice and Palliative Nursing Practice.* Pittsburgh, PA: Author.

Hospice and Palliative Care Nurses Association. (2000). *Standards of Nursing Practice and Professional Performance.* Pittsburgh, PA: Author.

Hospice and Palliative Nurses Association. (1997). *Hospice and Palliative Care Clinical Practice Protocol: Terminal Restlessness.* Pittsburgh, PA: Author.

Hospice and Palliative Nurses Association. (1999). *Hospice and Palliative Care Clinical Practice Protocol: Nausea and Vomiting.* Pittsburgh, PA: Author.

Hospice and Palliative Care Nurses Association. (1999). *Hospice and Palliative Nursing Practice Review.* Pittsburgh, PA: Author.

Hospice Nurses Association. (1996). *Hospice and Palliative Care Clinical Practice Protocol: Dyspnea.* Pittsburgh, PA: Author.

Jacox, A., Carr, D. B., Payne, R., et al. (1994). *Management of Cancer Pain: Clinical Practice Guideline, No. 9. AHCPR Publication No. 94-0592.* Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services, Public Health Service.

Joint Commission on Accreditation of Healthcare Organizations. (2000*). Pain Assessment and Management: An Organizational Approach.* Oak Brook Terrace, IL: Author.

Kuebler, K. K., English, N., & Heidrich, D. E. (2001). Delirium, confusion, agitation, and restlessness. In B. R. Ferrell & N. Coyle (Eds). *Textbook of Palliative Nursing.* New York, NY: Oxford University Press.

Kuebler, K., Dahlin, C., Ladd, L., Montonye, M., & Zeri, K. (1996). *Hospice and Palliative Care Clinical Practice Protocol: Dyspnea.* Pittsburgh, PA: Hospice and Palliative Nurses Association.

Last Acts. (2002). *Means to a better end: A report on dying in America.* Can be found online at http://www.lastacts.org

Last Acts Task Force. (1997). *Precepts of Palliative Care.* Princeton, NJ: Robert Wood Johnson Foundation. http://www.lastacts.org/docs/profprecepts.pdf

Lynn, J. (2000). Sick to death and not going to take it anymore. Accelerating change today for America's health. *Promises to Keep: Changing the Way We Provide End-of-Life Care.* Washington, DC: The National Coalition on Health Care, The Institute for Health Care Improvement.

Lynn, J., Schuster, J. L., & Kabcenell, A. (2000). *Improving Care for the End-of-Life: A Sourcebook for Health Care Managers and Clinicians.* New York, NY: Oxford University Press.

Medicare Payment Advisory Commission. Improving Care at the End of Life: Report to the Congress: Selected Medicare Issues. Washington, DC: Medicare Payment Advisory Commission; June 1999:117-132.

New Zealand Ministry of Health. The New Zealand Palliative Care Strategy. February 2001.

www.moh.govt.nz

National Hospice and Palliative Care Organization (2000 - check how to site, some pages say 2001 or 2002) *Standards of Practice for Hospice Programs*. Alexandria, VA: Author

National Hospice and Palliative Care Organization. (2001). *Complementary Therapies in End-of-Life Care*. Alexandria, VA: Author.

National Hospice and Palliative Care Organization. (1996). Press release: New findings address escalating end-of-life debate. Alexandria, VA: Author.

National Hospice and Palliative Care Organization. (2000). *Hospice Fact Sheet*. Alexandria, VA: Author.

National Hospice Organization, National Council for Hospice and Specialist in Palliative Care Services. (1997a). Making palliative care better: Quality improvement, Multiprofessional audit and standards. Arlington, VA: Author.

National Hospice Organization, Working Party on Clinical Guidelines in End-of-Life Care. (1997b). Changing gears: Guidelines for managing care in the last days of life in adults. Arlington, VA: Author.

National Hospice Organization. (1997c). A pathway for patients and families facing terminal illness. Arlington, VA: Author.

National Institutes of Health (1997). *Symptoms in Terminal Illness: A Research Workshop*. Retrieved from http://www.nih.gove/ninr/end-of-life.htm

Oncology Nursing Society. (1999). *Oncology Nursing Society Multicultural Outcomes: Guidelines for Cultural Competence*. Pittsburgh, PA: Author.

Oregon Death with Dignity Act. (1997). *Oregon Revised Statute 127800-127*: 897.

Patient Self-determination Act of 1990 (PSDA). (Sections 4206 and 4571 of the Omnibus Budget Reconciliation Act of 1990, PL 101-508). Effective December 1, 1991.

Palliative Care Australia www.pallcare.org.au/pca_aboutpalliativecare.html

Palliative Care Australia Development of Performance Indicators for Palliative Care in Australia. www.pallcare.org.au/publications/indicators/pca_development.html

Palliative Care Australia Standards for Palliative Care Provision, 3rd Edition, 1999. www.pallcare.org.au/publications/standards_99.pdf

Palliative Care Australia. Report of the National Census of Palliative Care Services for 1998. October, 1999.www.pallcare.org.au

Palliative Care Australia Service Provision in Australia: A Planning Guide, 2000. www.pallcare.org.au

Palliative Care Australia. Australia's Future in Palliative Care Research: A Collaborative Approach. September, 2000. www.pallcare.org.au

Project on Death in America and the Center on Crime, Communities, and Culture. (1999). Proceedings from the First National Conference on death and dying in prisons and jails: Caring for prisoners, families, and caregivers. *Journal of Law, Medicine, & Ethics, 27*(3).

Quill, T. E., & Byock, I. R. (2000). Responding to intractable terminal suffering: The role of terminal sedation and voluntary refusal of food and fluids. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians-American Society of Internal Medicine. [Consensus Development Conference. Guideline. Journal Article. Practice Guideline. Review]. *Annals of Internal Medicine, 132*, 408-14.

Standards Accreditation Committee, Medical Guidelines Taskforce (1996). *Guidelines for determining prognosis in non-cancer diseases* (2^{nd} ed.). Arlington, VA: National Hospice and Palliative Care Organization.

Standards and Quality Committee and Council of Palliative Care Australia, Palliative Care Australia. Resource Manual for Palliative Care Performance Indicators June 1998 copyright Commonwealth of Australia. www.pallcare.org.au/publications/indicators/pca_development.html

Staveteig S, Wigton A. Racial and Ethnic Disparities: Key Findings from the National Survey of America's Families. Assessing the New Federalism; National Survey of America's Families: an Urban Institute Program. 2000; B-5.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatment. *JAMA, 274*(20), 1591-1598.

Taylor, A., & Box, M. (1999). *Multicultural Palliative Care Guidelines*. Australia: Palliative Care Council of South Australia, Inc. Can be ordered online: http://www.pallcare.asn.au

Toolkit of Instruments to Measure End of Life Care http://www.chcr.brown.edu/pcoc/toolkit.htm

USDHHS. (2000). Healthy *People 2010: Understanding and Improving Health* [Report]. Washington, DC: United States Department of Health and Human Services, U. S. Government Printing Office.

Vacco v. Quill, 117 Sct 2293 (1997).

Vigano, A., Dorgan, M., Buckingham, J., et al. (2000). Survival prediction in terminal cancer patients: A systematic review of the medical literature. Palliative Medicine, 14, 353-374.

Von Gunten CF, Ferris FD, Portenoy RK, Glajchen M, eds. CAPC Manual: How to Establish a Palliative Care Program. New York, NY Center to Advance Palliative Care, 2001. Norms / Standards of Practice www.capc.org

World Health Organization (1990). Technical Support Series 804, Cancer Pain Relief and Palliative Care. Geneva: WHO.

Appendix 3

Advisory Committee Members

APPENDIX 4

Reference List

Author. (1998). The *Dartmouth atlas of health care.* Dartmouth Medical School. Center for the Evaluative Clinical Sciences Publication Information. American Hospital Publishing, Chicago, Ill.

American Board of Internal Medicine (ABIM). From the Committee on Evaluation of Clinical Competence. (1998). Caring *for the Dying*. Philadelphia, PA: Author.

Abrahm, J.L. (2000). A Physician's Guide to Pain and Symptom Management in Cancer Patients. Johns Hopkins University Press, Baltimore.

Allen, R.S., Haley, W.E., Small, B.J., & McMillan, S.C. (2002). Pain reports by older hospice patients and family caregivers: The role of cognitive functioning. *Gerontological Society of America,* 42(4), 507-514.

American Pain Society Quality of Care Committee. Quality improvement guidelines for the treatment of acute pain and cancer pain. JAMA 1995; 274:1874-1880.

Ambuel B. Conducting a family conference. Principles and Practices of Supportive Oncology Updates 1999; 3(3):1-12.

Avellanet, C. (2000). 1999 Annual report of Jacob Perlow Hospice. Beth Israel Medical Center, New York.

Baines MJ. ABC of palliative care: Nausea, vomiting, and intestinal obstruction. BMJ 1997; 315:1148-1150.

Bates MS, Sanchez-Ayendez M. The effects of the cultural context of health care on treatment of and response to chronic pain and illness. Social Science & Medicine. 1997; 45 (9): 1433-1447.

Berry, P., & Griffie, J. (2001). Planning for the actual death. In B. R. Ferrell, & N. Coyle (Eds.), *Textbook of Palliative Nursing.* New York, NY: Oxford University Press.

Billings, J. A., Block, S. D., Finn, J. W., LeGrand, S. B., Lupu, D., Munger, B., et al. (2002). Initial voluntary program standards for fellowship training in palliative medicine. *Journal of Palliative Medicine, 5*(1), 23-33.

Blackhall LJ, Murphy ST, Frank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. JAMA. 1995; 274:820-825.

Block SD for the ACP-ASIM End-of-Life Care Consensus Panel. Assessing and managing depression in the terminally ill patient. Ann Intern Med 2000; 132:209-218.

Boling, A., & Lynn J. (1998). Hospice: Current practice, future possibilities. *The Hospice Journal, 13*(1/2), 29-32.

Borum M, Lynn J, Zhong Z. The Effects of Patient Race on Outcomes in Seriously Ill Patients in SUPPORT: An Overview of Economic Impact, Medical Intervention, and End-Of-Life Decisions. Journal of the American Geriatrics Society. 2000; 48:S194-S198.

Bradley, E. H., Peiris, V. & Wetle, T. (1998). Discussions about end-of-life care in nursing homes. *Journal of the American Geriatric Society, 46*(10), 1235-1241.

Brown-Saltzman, K. (1998). Transforming the grief process. In R. Carroll-Johnson, L. Gorman, N. J. Bush. *Psychosocial Nursing Care: Along the Cancer Continuum*. Pittsburgh, PA: Oncology Nursing Press, Inc.

Bruera, E., & Fainsinger, R.L. (1998). Clinical management of cachexia and anorexia. In D. Doyle, G. W. C. Hanks, & N. MacDonald. (Eds.), *Oxford Textbook of Palliative Medicine*. New York, NY: Oxford University Press.

Bruera E, MacEachern T, Ripamonti C, Hanson J. Subcutaneous morphine for dyspnea in cancer patients. Annuls of Internal Medicine 1993; 119:906-907.

Buckman, R. (1998). Communication in palliative care: A practical guide. In D. Doyle, G. W. C Hanks, & N. MacDonald (Eds.), *Oxford Textbook of Palliative Medicine* (2nd ed.) (pp. 141-156). New York, NY: Oxford University Press.

Burrs FA. The African American experience: breaking the barriers to hospices. Hospice Journal.1995; 10(2):15-18.

Byock, I., Miles, S. (2003). Hospice Benefits and Phase I Cancer Trials. *Annals of Internal Medicine. 138(4):335-337, February 18, 2003.*

CAPC, Center to Advance Palliative Care. (Nov.2000). Planning a Hospital-based palliative care program: A primer for institutional leaders, Technical Assistance Series: Author.

Chochinov, H., Wilson K., Enns, M., & Lander, S. (1998). Depression, hopelessness and suicidal ideation in the terminally ill. *Psychosomatics, 39*(4), 366-370.

Christ, G., & Sormanti, M., (1999). Advancing social work practice in end-of-life care. *Social Work in Health Care*, 30(2), 81-99.

Covinsky, K. E., Fuller, J. D., Yaffe, K., Johnston, C. B., Hamel, M. B., Lynn, J., et al. (2000). Communication and decision-making in seriously ill patients: Findings of the SUPPORT project. *Journal of the American Geriatrics Society, 48*(5), S187-S193.

Corr, C. A. (1998). Death in modern society. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.) *Oxford Textbook of Palliative Medicine* (2nd ed.) (pp. 31-40). New York, NY: Oxford University Press.

Corless, I. B. (2001). Bereavement. In B. R. Ferrell, & N. Coyle (Eds.), *Textbook of Palliative Nursing Care*. New York, NY: Oxford University Press.

Corner J, Plant H, A'Hern R, Bailey C. Non-pharmacological intervention for breathlessness in lung cancer. Palliative Medicine 1996; 10:299-305.

Coyle, N. et al (1999). Care of the terminal patient's physical and psychosocial needs. In Miaskowski, C. and Buschnel, P. (Eds) Oncology Nursing: Assessment and Clinical Care. Mosby, St. Louis.

Coyle, N. (1997). Interdisciplinary collaboration in hospital palliative care: Chimera or goal? *Palliative Medicine, 11,* 265-266.

Crawley L, Payne R, Bolden J, Payne T, Washington P, Williams S. Palliative and End-of-Life Care in the African American Community. JAMA. 2000; 284: 2518-2521.

Cummings, I. (1998). The interdisciplinary team. In Doyle, D., Hanks, G. & MacDonald, N. (Eds.), Oxford Textbook of Palliative Medicine, (2nd ed.) (pp.20-30). Oxford: Oxford University Press.

Davis A. Ethics and ethnicity: end-of-life decisions in four ethnic groups of cancer patients. Med Law. 1996; 15 (3): 429-432.

Detmar SB, Muller MJ, Wever LDV, Schornagel JH, Aaronson NK. Patient-physician communication during outpatient palliative treatment visits: An observational study. JAMA 2001; 285:1351.

Donaldson MS, Filed MJ. Measuring quality at the end of life. Arch Intern Med 1998; 158:121-128.

Dowdy MD, Robertson C, Bander JA. A study of proactive ethics consultation for critically and terminally ill patients with extended lengths of stay. Critical Care Medicine, 1998; 26:252-259.

Du Pen SL, Du Pen AR, Polissar N, Hansberry J, Kraybill BM, Stillman M, Panke J, Everly R, Syrjala K. Implementing guidelines for cancer pain management: Results of a randomized controlled clinical trial. Journal of Clinical Oncology 1999; 17:361-370

Egan, K. A., & Labyak, M. J. (2001). Hospice care: A model for quality end-of-life care. In B. R. Ferrell, & N. Coyle (Eds.), *Oxford Textbook of Palliative Nursing.* New York, NY: Oxford University Press.

Eleazer GP, Hornung CA, et al. The relationship between ethnicity and advance directives in a frail older population. Journal of the American Geriatric Society. 1996; 44 (8): 938-943.

Ellershaw, J., Smith, C., Overill, S., Walker, S. E., & Aldridge, J. (2001). Care of the dying: Setting standards for symptom control in the last 48 hours of life. *Journal of Pain and Symptom Management, 21*(1), 12-17.

Emanuel, E. J., Ash, A. Yu, W., Gazelle, G., Levinsky, N., Saynina, O., McClellan, M., Moskowitz, M. (2002). Managed Care, Hospice Use, Site of Death, and Medical Expenditures in the Last Year of Life. *Archives of Internal Medicine. 162(15):1722-1728.*

Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. Ann Intern Med 2000; 132:451-459.

Faber-Langendoen K, Lanken PN for the ACP ASIM End-of-Life Care Consensus Panel. Dying patients in the intensive care unit: Forgoing treatment, maintaining care. Ann Intern Med 2000; 133:886-893.

Faber-Langerhorn, K. (1996). A multi-institutional study of care given to patients dying in hospitals. Ethical Practices and implications. *Arch Intern Med, 156*, 2540-2543.

Ferrell, B. R., & Coyle, N. (Eds.). (2001). *Textbook of Palliative Nursing*. New York, NY: Oxford University Press.

Ferrell, B. R., Virani, R., & Grant, M. (1999). Analysis of end-of-life content in nursing textbooks. *Oncology Nursing Forum, 26*(5), 869-876.

Ferrell, B. R., Juarez, G., Borneman, T., & ter Veer, A. (1999). Outcomes of pain education in community home care. *Journal of Hospice and Palliative Nursing, 1*(4), 141-150.

Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syne A, West P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

Fine, P. (1998). Processes *to Optimize Care During the Last Phase of Life*. Scottsdale, AZ: VistaCare Hospice, Inc.

Finlay IG & Jones RVH 1995. Definitions in palliative care. British Medical Journal, 311, p 754

Field, M. J., & Cassel, C. K. (Eds.). (1997). *Approaching Death: Improving Care at the End-of-Life* (Report of the Institute of Medicine Task Force). Washington, D.C.: National Academy Press.

Francke AL. Evaluative research on palliative support teams: A literature review. Pat Educ Couns 2000; 41:81-91.

Freeborne, N., Lynn, J., & Desbiens, N. A. (2000). Insights about dying from the SUPPORT project. *Journal of the American Geriatrics Society, 48*(5), S199-S205.

Friedman, B. T., Harwood, M. K., & Shields, M. (2002). Barriers and enablers to hospice referral: An expert overview. *Journal of Palliative Medicine, 5*(1), 73-84.

Given, C.S., Gwen, B., Azzoriz, F., Kozachik, S., & Stommel, N. (2001). Predictors of pain and fatigue in the year following diagnosis among elderly cancer patients. *Journal of Pain and Symptom Management.* 21(6), 456-466.

Glance, L. G., Osler, T., & Shinozaki, T. (1998). Intensive care unit prognostic scoring systems to predict death: A cost-effective analysis. *Critical Care Medicine*, 26(11), 1842-1849.

Glass, E., Cluxton, D., & Rancour, P. (2001). Principles of patient and family assessment. In B. R. Ferrell, & N. Coyle (Eds.), *Textbook of Palliative Nursing*. New York, NY: Oxford University Press.

Goetschius, S.K. (2001). Caring for Families: The Other Patient in Palliative Care in Matzo, M. L., & Sherman, D. W. (Eds.). *Palliative Care Nursing: Quality Care to the End of Life*. New York, NY: Springer Publishing Company.

Grant, M., & Hanson, J. (2002). Issues and opportunities in quality end-of-life care. *Journal of Oncology Management, Mar/Apr, 11*(2), 22-24.

Grossman, S. A., Benedetti, C., Payne, R., & Syrjala, K. (1999). NCNN practice guidelines for cancer pain. *Oncology, 13*, 33-44.

Hallenbeck J, Goldstein MK. Decisions at the end of life: cultural considerations beyond medical ethics. Generations Spring; 1999: 24-29.

Hallenbeck JG, Mebane EW. Cultural considerations of death and dying in the United States. Clinical Geriatric Medicine. 1996; 12 (2): 393-406.

Hamel MB, Teno JM, Goldman L, Lynn J, Davis RB, Galanos AN, Desbiens N, Connors AF, Wenger N, Phillips RS. for the Support Investigators. Patient age and decisions to withhold life-sustaining treatments from seriously ill, hospitalized adults. Ann Intern Med 1999; 130:116-125.

Hammes BJ, Rooney BL. Death and end-of-life planning in one Midwestern community. Arch Intern Med 1998; 158:383-90.

Hastings Center. (1987). *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*. Bloomington, IN: University Press.

Hazzard, W. R., Woolard, N., & Regenstreif, D. I. (2001). Internal medicine: At the nexus of the health care system in responding to the demographic imperative of an aging population. *The American Journal of Medicine, 110* (6), 507-513.

Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: A review. J Public Health Med 1997; 19:193-199.

Hermann, C. & Looney, S. (2001). The effectiveness of symptom management in hospice patients during the last seven days of life. *Journal of Hospice and Palliative Nursing, 3*(3), 88-96.

Highfield, M. E. F. (2000). Providing spiritual care to patients with cancer. *Clinical Journal of Oncology Nursing, 4*(3), 115-120.

Hopp FP. Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: Results from a national study. The Gerontologist. 2000; 40 (4): 449-457.

Hopp FP, Duffy SA. Racial Variations in End-of-Life Care. Journal of the American Geriatrics Society. 2000; 48: 658-663.

IOM Crossing the Quality Chasm: A New Health System for the 21st Century. Washington DC: National Academy Press; 2001

Jacox, A., Carr, D. B., Payne, R., et al. (1994). *Management of Cancer Pain: Clinical Practice Guideline, No. 9. AHCPR Publication No. 94-0592.* Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services, Public Health Service.

Jennings B, Ryndes T, D'Onofrio C, Baley M.. *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, Hastings Center Report Special Supplement 33, no 2 (2003), pp S3-59.

Joint Commission on Accreditation of Hospitals Organization. (1999).
Available: http://www.jcaho.org

Kagawa-Singer M. A multicultural perspective on death and dying. Oncology Nurse Forum 1998; 25(10):1751-1763.

Kagawa-Singer M. Cultural systems. In R. McCorkle et al (Eds). Cancer Nursing (2nd ed). Philadelphia: Saunders 1996: 38-52.

Keovilay L, Rasbridge L, Kemp C. Cambodian and Laotian Health Beliefs and Practices Related to the End of Life. Journal of Hospice and Palliative Medicine. 2000; 2 (4):143-151.

Koenig, B. A. (1997). Cultural diversity in decision-making about care at the end of life. In M. J. Field & C. K. Cassel (Eds.), *Approaching Death: Improving Care at the End of Life*. (pp. 363-382). Washington, DC: Institute of Medicine, National Academy Press.

Koenig, B. A., & Gates-Williams, J. (1995). Understanding cultural differences in caring for dying patients. *Western Journal of Medicine, 163*(3), 244-249.

Krammer, Ring, Martinez, Jacobs & Williams (2001). The Nurse's Role in Interdisciplinary and Palliative Care in Matzo, M. L., & Sherman, D. W. (Eds.). (2001). *Palliative Care Nursing: Quality Care to the End of Life*. New York, NY: Springer Publishing Company.

Kristjanson, L. (2001). Establishing goals of care: Communication traps and treatment lane changes. In B. R. Ferrell, & N. Coyle (Eds.), *Textbook of Palliative Nursing*. New York, NY: Oxford University Press.

Kristjanson LJ. The family as the unit of treatment. In Portenoy, R. & Bruera, E. (Eds). Topics in Palliative Care (Volume 1), New York, Oxford University Press, 245-261, 1997.

Kuebler, K. K., English, N., & Heidrich, D.E. (2001). Delirium, confusion, agitation, and restlessness. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of Palliative Nursing*. New York, NY: Oxford University Press.

Kuebler, K., Dahlin, C., Ladd, L., Montonye, M., & Zeri, K. (1996). *Hospice and Palliative Care Clinical Practice Protocol: Dyspnea*. Pittsburgh, PA: Hospice and Palliative Nurses Association.

Lamberg, L. (2002). "Palliative care" means "active care": It aims to improve quality of life. *JAMA, 288*(8), 943-944.

Langford, J. M. (2000). *Death and Dying in Ethnic America: Findings in Lao Lum, Khmu, Hmong, Kher, and Cham Communities*. Seattle, WA: The Cross Cultural Health Care Program.

Larson DG, Tobin DR. End-of-life conversations: Evolving practice and theory. JAMA 2000; 284:1573.

Last Acts. (2002). *Means to a better end: A report on dying in America.* Can be found online at http://www.lastacts.org

Last Acts Task Force. (1997). *Precepts of Palliative Care.* Princeton, NJ: Robert Wood Johnson Foundation.

Levine, C. (2000). The many worlds of family caregivers. In Levine, C. (Ed.). *Always on Call, when illness turns families into caregivers.*

Lo, K. (2000). Dignified *Care of the Actively Dying Resident.* Largo, Fl: The Hospice Institute of the Florida Suncoast.

Lo, K. (1996). *Care At the Time of Death.* Largo, FL: The Hospice Institute of the Florida Suncoast.

Lo B, Quill T, Tulsky J for the ACP-ASIM End-of-Life Care Consensus. Discussing Palliative Care with Patients. Ann Intern Med 1999; 130:744-749.

Lo, B., Snyder, L., & Sox, H. Care at the end of life: Guiding practice where there are no easy answers. Ann Intern Med 1999; 130:772-774

Loudon RF, Anderson PM, Gill PS, Greenfield SM. Educating Medical Students for Work in Culturally Diverse Societies. JAMA. 1999; 282 (9): 875-880.

Lynn, J. (2000). Sick to death and not going to take it anymore. Accelerating change today for America's health. *Promises to Keep: Changing the Way We Provide End-of-Life Care.* Washington, DC: The National Coalition on Health Care, The Institute for Health Care Improvement.

Lynn, J. (2001). Serving patients who may die soon and their families: The role of hospice and other services. *JAMA, 285*(7), 925-932.

Lynn, J., Schuster, J. L., & Kabcenell, A. (2000). *Improving Care for the End-of-Life: A Sourcebook for Health Care Managers and Clinicians.* New York, NY: Oxford University Press.

Lynn J. Measuring quality of care at the end of life: a statement of principles. J Am Geriatric Soc 1997; 45:526-527.

Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF Jr. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatments. Ann Intern Med 1997; 126:97-106.

MacDonald, N. (2002). Redefining symptom management. *Journal of Palliative Medicine, 5*(2), 301-304.

Mann, S.M. & Welk, T.A. (1997). Hospice and/or palliative care? *American Journal of Hospice and Palliative Care, 14,* 314-315.

Mannix, K. A. (1998). Palliation of nausea and vomiting. In D. Doyle, G. W. C. Hanks, & N. MacDonald. (Eds.) *Oxford Textbook of Palliative Medicine.* New York, NY: Oxford University Press.

Mariano, C., (2001). Holistic Integrated Therapies in Palliative Care, in Matzo, M. L., & Sherman, D. W. (Eds.). *Palliative Care Nursing: Quality Care to the End of Life.* New York, NY: Springer Publishing Company.

Massie MJ, Payne DK. Depression and anxiety. In Berger A et al. (Eds), Principles and Practice of Supportive Oncology, Philadelphia, Lincot-Raven Publishers, Philadelphia, 1999.

Matzo, M. L., & Sherman, D. W. (Eds.). (2001). *Palliative Care Nursing: Quality Care to the End of Life.* New York, NY: Springer Publishing Company.

Matzo, M.L. (2001). Peri-Death Nursing Care in Matzo, M. L., & Sherman, D. W. (Eds.) *Palliative Care Nursing: Quality Care to the End of Life.* New York, NY: Springer Publishing Company.

McGlynn EA, Cassel CK, Leatherman ST et al. Establishing national goals for quality improvement. Medical Care 2003; 41: I-16 – I-29.

McCarthe M, Higginson I. Clinical audit by a palliative care team. Palliative Med 1991; 5:215-221.

McWhinney IR, Bass MJ, Donner A. Evaluation of a palliative care service: Problems and pitfalls. BMJ 1994; 309: 1340-1342.

Meier, D.E. (2003).When pain and suffering do not require a prognosis. *Journal of Palliative Medicine, 6(1),* 109-115.

Meier, D. E. (2002). United States: Overview of cancer pain and palliative care. *Journal of Pain and Symptom Management, 24*(2), 265-269.

Meier DE. Palliative care in hospitals: Making the case. New York. Center to Advance Palliative Care, 2002.

Mezey, M., Teresi, J., Ramsey, G., Mitty, E., & Bobrowitz, T. (2000). Decision-making capacity to execute a health care proxy: Development and testing of guidelines. *Journal of the American Geriatrics Society, 48*(2), 179-187.

Midwest Bioethics Center. (2001) Advance care planning – Part I. *State Initiatives in End-of-Life Care, 12,* 1-8.

Miles SH, Koe, R, Weber EP. Advance end-of-life treatment planning: A research review. Arch Intern Med 1996; 156:1062-1068.

Miller, P., Hedlund, S., Murphy, K. (1998). Social work assessment at the end of life: Practical guidelines for suicide and the terminally ill. *Social Work in Health Care*, 26(4), 23-36.

Miller RD, Walsh D. Psychosocial aspects of palliative care in advanced cancer. J Pain Symptom Manage 1991; 6(1):24-29.

Miller S et. al. Synthesis and analysis of Medicare's Hospice Benefit, executive summary and recommendations, Washington DC: US Department of Health and Human Services, March 2000.

Mitty, E. L. (2001). Ethnicity & end-of-life decision-making. *Reflections on Nursing Leadership, 27*(1), 28-31, 46.

Monroe, B. (1998). Social work in palliative care. In Doyle, D. et al (Eds). *Oxford Textbook of Palliative Medicine*, Oxford Medical Publications, New York, p 868.

Morrison, R.S., Siu, A. L., Leipzig, R.M., Cassel, C.K., Meier, D., (2000). The Hard Task of Improving the Quality of Care at the End of Life. *Archives of Internal Medicine. 160(6):743-747.*

Morrison RS, Siu AL, Leipzig RM, Cassel CK, Meier DE. The hard task of improving the quality of care at the end of life. Arch Intern Med 2000; 160:743-747.

Morrison RS, Zayas LH, Mulvihill M, Baskin SA, Meier DE. Barriers to Completion of Health Care Proxies. Arch Intern Med. 1998; 158: 2493-2497.

Morita, T., Tsundoa, J., Inoue, S., et al. (1999). Validity of the palliative performance scale from a survival perspective. *Journal of Pain and Symptom Management, 18*, 2-3.

National Hospice and Palliative Care Organization. (2003). *Facts and Figures*. Alexandria, VA: Author.

National Hospice and Palliative Care Organization. (2001). *Complementary Therapies in End-of-Life Care*. Alexandria, VA: Author.

National Hospice and Palliative Care Organization. (2000a). *Standards of Practice for Hospice Programs*. Alexandria, VA: Author.

National Hospice and Palliative Care Organization. (2000b). *Hospice Fact Sheet*. Alexandria, VA: Author.

NHO Standards and Accreditation Committee. (1997). *A Pathway for Patients and Families Facing Terminal Illness*. Arlington, VA: National Hospice Organization.

National Institutes of Health (1997). *Symptoms in Terminal Illness: A Research Workshop*. Retrieved from http://www.nih.gove/ninr/end-of-life.htm

National Hospice Organization (NHO). (1996). *Time Line Phases of Terminal Care*. Alexandria, VA: Author.
National Hospice Organization, February 1979, *Standards of a Hospice Program of Care*,

Norton, S. A., & Talerico, K. A. (2000). Facilitating end-of-life decision-making: Strategies for communicating and assessing. *Journal of Gerontological Nursing, 26*(9), 6-13.

Novak, B., Kolcaba, K., Steiner, R., & Dowd, T. (2001). Measuring comfort in caregivers and patients during late end-of-life care. *American Journal of Hospice & Palliative Care, 18*(3), 170-180.

O'Connor, P. (1993). Clinical paradigm for exploring spiritual concerns. In K. Doka & J. Morgan (Eds.), *Death and Spirituality*. New York, NY: Baywood Publishing Company.

Oncology Nursing Society. (1999). *Oncology Nursing Society Multicultural Outcomes: Guidelines for Cultural Competence.* Pittsburgh, PA: Author.

O'Neill B, Fallon M. ABC of palliative care: Principles of palliative care and pain control. BMJ 1997; 315:801-804.

Pasacreta, J., Minarik, P., & Nield-Anderson, L. (2001). Anxiety and depression. In B. R. Ferrell, & N. Coyle. (Eds.), *Textbook of Palliative Nursing.* New York, NY: Oxford University Press.

Patterson, L. B., & Dorfman, L. T. (2002). Family support for hospice caregivers. *American Journal of Hospice & Palliative Care, 19*(5), 315-324.

Perrin, K.O. (2001). Communicating with Seriously Ill and Dying Patients, Their Families, and Their Health Care Provider, in Matzo, M. L., & Sherman, D. W. (Eds.). *Palliative Care Nursing: Quality Care to the End of Life*. New York, NY: Springer Publishing Company.

Pickett, M. & Yancey, D. (1998). Symptoms of the dying. In R. McCorkle, M. Grant, M. Frank-Stromborg, & S. Baird (Eds.), *Cancer Nursing: A Comprehensive Textbook* (2nd ed.) (pp. 1157-1182). Philadelphia, PA: W.B. Saunders Company.

Portenoy, R. K. (1998). Defining palliative care. Newsletter: Department of Pain Medicine and Palliative Care, 1(2) 1-2. Beth Israel Medical Center, New York. Available: http://www.stoppain.org (January 4, 2000)

Post, L.F., & Dubler, N.N. (1997). Palliative care: A bioethical definition, principles, and Clinical guidelines. *Bioethics Forum, 13*(3), 17-24.

Potter, M. (2001). Loss, Suffering, Bereavement, and Grief, in Matzo, M. L., & Sherman, D. W. (Eds.). (2001). *Palliative Care Nursing: Quality Care to the End of Life*. New York, NY: Springer Publishing Company.

Pritchard RS, Fisher ES, Teno JM, Sharp SM, Reding DJ, Knaus WA, et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc. 1998;46:1242-50

Quill TE. Initiating end-of-life discussions with seriously ill patients: Addressing the elephant in the room. JAMA 2000; 284:2502.

Ramsey, G. Legal Aspects of Palliative Care, in Matzo, M. L., & Sherman, D. W. (Eds.). (2001). *Palliative Care Nursing: Quality Care to the End of Life*. New York, NY: Springer Publishing Company.

Ramirez A, Addington-Hall J, Richards M. ABC of palliative care: The carers. BMJ 1998; 316:208-211

Reese, D., Raymer, M., & Richardson, J. (2000, March). National hospice social work survey: Summary of final results. National Hospice & Palliative Care Organization.

Roy, D. J., & MacDonald, N. (1998). Ethical issues in palliative care. In D. Doyle, G. W. C. Hanks, & N. MacDonald. (Eds.), *Oxford Textbook of Palliative Medicine*. New York, NY: Oxford University Press.

Rudberg MA, Teno JM, Lynn J. Developing and implementing measures of quality of care at the end of life: A call for action. J Am Geriatric Soc 1997; 45:528-530

Ryndes, T. The good life, the good death: new beginnings in hospice. *Healthcare Forum J.* 1995 Mar-Apr;38(2):27-9.

Ryndes T, Emanuel L. Is discontinuity in palliative care a culpable act of omission? *Hastings Center Report Special Supplement 33*, no. 2 (2003) pp S45-S47.

Saunderson EM, Ridsdale L, Jewell D. General practitioners' beliefs and attitudes about how to respond to death and bereavement: Qualitative study commentary: Use of personal experience should be legitimized. BMJ 1999; 319:293-296.

Scanlon, C. (1998). Unraveling ethical issues in palliative care. *Seminars in Oncology Nursing, 14*(2), 1-9.

Scanlon, C., & Rushton, C. (1998). A road map for navigating end-of-life care. *Med Surg Nursing, 7*(1), 57-59.

Scanlon, C. (1997). Defining standards for end-of-life care. *American Journal of Nursing, 97*(11), 58-60.

Schapiro R, Byock I. Living and dying well with cancer: successfully integrating palliative care and cancer treatment. Robert Wood Johnson Foundation: Promoting Excellence in the End of Life. 2003. pp. 7-15.

Schwarz, J.K. Ethical Aspects of Palliative Care in .Matzo, M. L., & Sherman, D. W. (Eds.). (2001). *Palliative Care Nursing: Quality Care to the End of Life*. New York, NY: Springer Publishing Company.

Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA 1999; 281:163-168.

Skolnick AA. MediCaring project to demonstrate, evaluate innovative end-of-life program for chronically ill. JAMA 1998; 279:1511.

Smeenk FWJM, de Witte LP, Nooyen IWCJ, Crebolder HFJM. Effects of transmural care on coordination and continuity of care. Pat Educ Couns 2000; 41:73-81.

Smeenk FWJM, van Haastregt JCM, de Witte LP, Crebolder HFJM. Effectiveness of home care programmes for patients with incurable cancer on their quality of life and time spent in hospital: Systematic review. BMJ 1998; 316: 1939-1944.

Solomon, N. R. Z. (2000). *Death and Dying in Ethnic America: Findings in Eritrean, Oromo, and Somali Communities*. Seattle, WA: The Cross-cultural Health Care Program.

Solomon, M.Z., & Jennings, B. (1998). Palliative care for Alzheimer's patients: Implications for institutions, caregivers, and families. In L. Volicer, & A. Hurley (Eds.), *Hospice care for patients with advanced progressive dementia* (pp. 132-154). New York: Springer Publishing Company.

Speck, P. (1998). Spiritual issues in palliative care. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Textbook of Palliative Care*, (pp. 805-814). New York, NY: Oxford University Press.

Spross, J. A. (1996). Coaching and suffering. In B. R. Ferrell (Ed.), *Suffering* (pp. 3-27). Sudbury, MA: Jones and Bartlett Publishers.

Stanley, K. J., & Zoloth-Dorfman, L. (2001). Ethical considerations. In B. R. Ferrell & N. Coyle (Eds.). *Textbook of Palliative Nursing*. New York, NY: Oxford University Press.

Stanley, K. (2000). Silence is not golden: Conversations with the dying. *Clinical Journal of Oncology Nursing, 4*(1), 34-40.

Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end-of-life by patients, family, physicians, and other care providers. *JAMA, 284*(19), 2476-2482.

Steinhauser KE, Cli EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: Observations of patients, families and providers. Ann Intern Med 2000; 132:825-832.

Sulmasy, D. P. (1997). *The Healer's Calling*. New York/Mahway, NJ: Paulist Press.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatment. *JAMA, 274*(20), 1591-1598.

Taylor, A., & Box, M. (1999). ***Multicultural Palliative Care Guidelines***. Australia: Palliative Care Council of South Australia, Inc. Can be ordered online: http://www.pallcare.asn.au

Teno, J.M. (2003). *Facts On Dying: Policy relevant data on care at the end of life.* Center for Gerontology and Health Care Research at the Brown Medical School.

Teno JM. Clarridge B. Casey V. Edgman-Levitan S. Fowler F. (2001). Validation of Toolkit After-Death Bereaved Family Member Interview. *Journal of Pain & Symptom Management. 22(3):752-8.*

Teno, J., Byock, I., & Field, M. (1999). Research agenda for developing measures to examine quality of care and quality of life of patients diagnosed with life limiting illness. *Journal of Pain and Symptom Management, 17*(2), 75-82.

Teno, J., Fisher, E., Hamel, M. B., Wu, A. W., Murphy, D. J., Wenger, N. S., Lynn, J., & Harrell, F. E. (2000). Decision-making and outcomes of prolonged ICU stays in seriously ill patients. *Journal of the American Geriatrics Society, 48*(5), S70-S74.

Ternestedt, B., Andershed, B., Eriksson, M., & Johansson, I. (2002). A good death: Development of a nursing model of care. *Journal of Hospice and Palliative Nursing, 4*(3), 153-160.

Thompson, G., & McClement, S. (2002). Defining and determining quality in end-of-life care. *International Journal of Palliative Nursing, 8*(6), 288, 290-293

Thorns, A., & Sykes, N. (2000). Opioid use in last week of life and implications for end-of-life decision-making. *Lancet, 356*(9227), 398-399.

Tolle SW, Rosenfeld AG, Tilden VP & Park Y. Pregon's low in-hospital death rates: what determines where people die and satisfaction with decisions on place of death? Annals of Internal Medicine. 1999; 130: 681-685.

Tolle, S. W., Tilden, V. P., Rosenfeld, A. G., & Hickman, S. E. (2000). Family reports of barriers to optimal care of the dying. *Nursing Research, 49*(6), 310-317.

Travis, S.S, & Larsen, P.D. (in press) Palliation and End of Life Care Across Health Care Settings. in Matzo, M. & Sherman, D.W. Gerontological Palliative Care Nursing: Care Across Illness Trajectories, Mosby.

United Hospital Fund. (1998). *The Challenge of Caring for Patients Near the End-of-Life: Findings from the Hospital Palliative Care Initiative*. New York, NY: Author.

von Gunten, C. F. (2002a). Discussing hospice care. *Journal of Clinical Oncology, 20*(5), 1419-1424.

von Gunten, C. F. (2002b). Secondary and Tertiary Palliative Care in US Hospitals. *JAMA*, 287(7):875-881.

von Gunten, C. F., Ferris, F. D., & Emanuel, L. L. (2000). Ensuring competency in end-of-life care: Communication and relational skills. *Journal of the American Medical Association, 284*(23), 3051-3057.

Waters CM. End-of-life care directives among African-Americans: Lessons learned-A need for community-centered discussion and education. Journal of Community Health Nursing. 2000; 17 (1): 25-37.

Wenger, N. S., Phillips, R. S., Teno, J. M., Oye, R. K., Dawson, N. V., Liu, H., et al. (2000). Physician understanding of patient resuscitation preferences: Insights and clinical implications. *Journal of the American Geriatrics Society, 48*(5), S44-S51.

Wrede-Seaman, L. (1999). *Symptom Management Algorithms - A Handbook for Palliative Care.* Yakima, WA: Intellicard. www.intelli-card.com

Yates, P., & Stetz, K. M. (1999). Families' awareness of and response to dying. *Oncology Nursing Forum, 26*(1), 113-120.

Zabora, J. & Loscalzo, M. (1998). Psychosocial consequences of advanced cancer. In Berger, A. et al. (Eds). Principles and Practices of Supportive Oncology, Lippincott-Raven Publishers, Philadelphia: PA, 531-545.

Zoucha, R. (2000). The keys to culturally sensitive care. *American Journal of Nursing, 100*(2), 24GG-24II.

Zuckerman, C. (1999). Looking beyond the law to improve end-of-life care. *Generations: Journal of the American Society on Aging, 23*(1), 30-35.

ATTACHMENT C

SELECTED PROVISION OF THE BYLAWS OF NCSBN

From NCSBN Bylaws as revised 8/11/01 and present at the 2003 NCSBN Annual Meeting

Article II

Purpose and functions
Section 1. *Purpose*. The purpose of the National Council is to provide an organization through which state boards of nursing act and counsel together on matters of common interest and concern affecting the public health, safety and welfare, including the development of licensing examination in nursing.

Section 2. *Functions.* The National Council's functions shall include but not be limited to providing services and guidance to its members in performing their regulatory functions regarding entry into nursing practice, continued safe nursing practice and nursing education programs. The National Council provides Member Boards with examinations and standards for licensure and credentialing; promotes uniformity in standards and expected outcomes in nursing practice and education as they related to the protection of the public health, safety and welfare; provides information, analyses and standards regarding the regulation of nursing practice and nursing education; promotes the exchange of information and serves as a clearinghouse for matters related to nursing regulation.

Article II
Members

Section 2. *Qualifications.* Any state board of nursing that agrees to use one or more National Council Licensing Exams (the "NCLEX® examination" under the terms and conditions specified by the National Council and pays the required fees may be a member of the National Council ("Member Board").

Section 3. *Admission.* A state board of nursing shall become a member of the National Council and be known as a Member Board upon approval by the Delegate Assembly, as described in Article IV, payment of the required fees and execution of a contract for using the NCLEX® examination.

Section 6. *Privileges.* Membership privileges include but are not limited to the right to vote as prescribed in these bylaws and the right to assist in the development of the NCLEX® examination, except that a Member Board that uses both the NCLEX examination and another examination leading to the same license shall not participate in the development of the NCLEX examination to the extent that such participation would jeopardize the integrity of the NCLEX examination.

Section 7. ***Noncompliance.*** Any Member Board whose fees remain unpaid after January 15 is not in good standing. Any Member Board which does not comply with the provisions of the bylaws and contracts of the National Council shall be subject to immediate review and possible termination by the Board of Directors.

Section 9. ***Reinstatement.*** A Member Board in good standing that chooses to terminate membership shall be required to pay only the current fee as a condition of future reinstatement. Any membership which has been terminated for nonpayment of fees shall be eligible for reinstatement to membership upon payment of the current fee and any delinquent fees.

Article IV
Delegate Assembly

Section 1. ***Composition....***
b) *Qualification of Delegates*. Members and employees of Member Boards shall be eligible to serve as delegates until their term or their employment with a Member Board ends. A National Council officer or director may not represent a Member Board as a delegate.

Section 3. ***Authority.*** The Delegate Assembly, the membership body of the National Council, shall provide direction for the National Council through resolutions and enactments, including the adoption of the mission and strategic initiatives, at any Annual Meeting or special session. The Delegate Assembly shall approve all new National council memberships; approve the substance of the NCLEX examination contracts between the National Council and Member Boards; adopt test plans to be used for the development of the NCLEX examination; approve the NCLEX examination test service; and establish the fee for the NCLEX examination.

Article V
Officers and Directors

Section 3. ***Qualifications.*** Members and employees of Member Boards shall be eligible to serve as National Council officers and directors until their term or their employment with a Member Board ends. Members of a Member Board who become permanent employees of a Member Board will continue their eligibility to serve.

Section 7. ***Limitations.*** No person may hold more than one officer position or directorship at one time. No officer or director shall hold elected or appointed office or a salaried position in a state, regional or national association or body if the office or position might result in a potential or actual, or the appearance of, a conflict of interest with the National Council, as determined by the Committee on Nominations before election to office and as determined by the Board of Directors after election to office....

Article VI
Board of Directors

Section 2. ***Authority.*** The Board of Directors shall transact the business and affairs and act on behalf of the National Council except to the extent such powers are reserved to the Delegate Assembly as set forth in these bylaws and provided that none of the Board's acts shall conflict with resolutions or enactments of the Delegate Assembly. The Board of Directors shall report annually to the Delegate Assembly.

Article VIII
Meetings

Section 1. ***Participation.***

a) Delegate Assembly Session.

(i) *Member Boards.* Members and employees of Member Boards shall have the rights, subject to the Standing Rules of the Delegate Assembly, to speak at all open sessions and forums of the Delegate Assembly, provided that only delegates shall be entitled to vote and only delegates and members of the Board of Directors may make motions at the Delegate Assembly, except the Examination Committee may bring motions to approve test plans pursuant to Article X, Section 1(a).

(ii) *Public.* All sessions of the Delegate Assembly held in accordance with Sections 4 and 5 of Article IV of these bylaws shall be open to the public, except executive sessions, provided that the minutes reflect the purpose of, and any action taken in, executive session.

Article X
Section 1. ***Standing Committees.*** National Council shall maintain the following standing committees.

a) *Examination Committee.* The Examination Committee shall be comprised of at least nine members. One of the committee members shall be a licensed practical/vocational nurse or a board or staff member of an LPN/VN board. The committee chair shall have served as a member of the committee prior to being appointed as chair. The Examination Committee shall provide general oversight of the NCLEX® examination process, including examination item development, security, administration and quality assurance to ensure consistency with the Member Boards' need for examinations. The Examination Committee shall approve item development panels and recommend test plans to the Delegate Assembly. Subcommittees may be appointed to assist the Examination Committee in the fulfillment of its responsibilities.

...

c) *Practice, Regulation, and Education Committee.* The Practice, Regulation, and Education Committee shall be comprised of at least six members. The Committee shall provide general oversight of nursing practice, regulation, and education issues.

Section 2. ***Special Committees.*** The Board of Directors may appoint special committees as needed to accomplish the mission of the National Council and to assist any Standing Committee in the fulfillment of its responsibilities. Special committees may include subcommittees, task forces, focus groups, advisory panels or other groups designated by the Board of Directors.

...

Section 4. ***Committee Membership.***

a) *Composition.* Membership of Standing and Special committees shall be appointed by the Board of Directors. Standing committees shall include only current members and employees of Member Boards. Special committees may also include consultants or other individuals selected for their special expertise to accomplish a committee's charge. In appointing committees, one representative from each Area shall be selected unless a qualified member from each Area is not available considering the expertise needed for the committee work. The president, or president's delegate, shall be an ex-officio member of all committees except the Committee on Nominations.