

ADVANCED PRACTICE NURSES ROLE IN PALLIATIVE CARE

A Position Statement from American Nursing Leaders

PARTICIPANTS AND ENDORSERS

Corrine Anderson, MSN, RN, GNP, CHPN
Nurse Practitioner, Palliative Care
Community Center for Palliative Care
Fort Worth, TX

Judith Gedney Baggs, PhD, RN, FAAN
Professor & Associate Dean of Academics
University of Rochester School of Nursing
Rochester, NY

Margaret Campbell, RN, MSN, FAAN
Nurse Practitioner, Palliative Care Service
Detroit Receiving Hospital
Detroit, MI

Nessa Coyle, RN, MS, FAAN
Director of the Supportive Care Program,
Palliative Care Service
Department of Neurology,
Memorial Sloan-Kettering Cancer Center
New York, NY

Constance M. Dahlin, RN, CS, MSN, ANP
Advanced Practice Nurse, Palliative Care Service
Massachusetts General Hospital
Boston, MA

Peg Esper, RN, MSN, NP-BC, AOCN
Nurse Practitioner, Medical Oncology
Comprehensive Cancer Center
Medical Oncology Department,
University of Michigan
Ann Arbor, MI

Betty Ferrell, PhD, RN, FAAN[†]
Research Scientist
City of Hope National Medical Center
Duarte, CA

Debra Heidrich, RN, MSN, CHPN, AOCN
Nursing Consultant
West Chester, OH

Martha Henderson, MSN, MDiv, DrMin, GNP
Clinical Assistant Professor of Nursing
Program on Aging
School of Nursing
University of North Carolina
Chapel Hill, NC

Michelle Hobbs, RN, MS, CNP
Family Nurse Practitioner
President
Palliative Care Concepts, Inc.
Greenville, OH

Karin Kirchhoff, PhD, RN, FAAN
Rodefer Chair & Professor
Madison School of Nursing
University of Wisconsin
Madison, WI

Jane Kirschling, RN, DNS
Dean, College of Nursing and Health Professions,
& Professor of Nursing
University of Southern Maine
Portland, ME

Kim K. Kuebler MN, RN, ANP-CS[†]
Palliative Care Nurse Practitioner
Private Practice
Adjuvant Therapies Inc
Lake, MI

Judy Lentz, RN, MSN, OCN, NHA
Executive Director
Hospice & Palliative Nurses Association
Pittsburgh, PA

Ruth McCorkle, RN, PhD, FAAN
Professor & Chair, Doctoral Program
Yale University School of Nursing
New Haven, CT

Susan McMillan, PhD, ARNP, FAAN
College of Nursing
University of South Florida
Tampa, FL

Patricia Murphy, PhD, APN, FAAN
APN Ethics and Bereavement
University of Medicine and Dentistry
of New Jersey—University Hospital
Newark, NJ

Mary Jo Perley, PhD, RN,
Psychiatric Mental Health Nurse Practitioner
Assistant Clinical Professor
The University of Texas
Arlington School of Nursing
Arlington, TX

Anne Rhome, RN, MPH
Deputy Executive Director
American Association of Colleges of Nursing
Washington, DC

Cynda Hylton Rushton, DNSc, RN, FAAN
Johns Hopkins University and Children's Center
Baltimore, MD

Colleen Scanlon, RN, MS, JD
Senior Vice President, Advocacy
Catholic Health Initiatives
Denver, CO

Denise Sheehan, RN, MSN
Coordinator, Palliative Care Program
The Breen School of Nursing
Ursuline College
Pepper Pike, OH

Diana Wilkie, PhD, RN[†]
Professor & ACS Professor of Oncology Nursing
Biobehavioral Nursing and Health Systems
University of Washington School of Nursing
Seattle, WA

Deborah Witt Sherman, PhD, APRN, ANP, BC, FAAN
Associate Professor and Program Coordinator
Advanced Practice Palliative Care Master's
and Post-Master's Programs
New York University
New York, NY

ADVANCED PRACTICE NURSES ROLE IN PALLIATIVE CARE

A Position Statement from American Nursing Leaders

Dear Colleague,

Nurse specialists play an essential role in delivering palliative care in a variety of settings and circumstances in the United Kingdom and other parts of the world. Recognizing the work of pioneering advanced practice nurses in the United States, the *Promoting Excellence in End-of-Life Care* national program of The Robert Wood Johnson Foundation convened a group of acknowledged leaders in American nursing to consider the state of advanced practice nursing in palliative care and make recommendations for future development of this specialty focus of nursing practice.

On July 9 and 10, 2001, a meeting of the listed participants was held in Philadelphia. The discussions and deliberations of the meeting built on a survey and interview with the participants and other “key informants” in the field of palliative care nursing. A writing team comprised of Constance Dahlin, Meg Campbell and Ruth McCorkle drafted a statement reflecting the consensus of those present at the July 2001 meeting. The draft was circulated to the attendees and underwent multiple iterations. The final statement represents a consensus of those signatories.

The Promoting Excellence in End-of-Life Care program is pleased to support the dissemination of this statement and the recommendations it contains. Advanced practice nursing specialists with expertise in palliative care represent a critical resource for meeting the needs of dying Americans and their families.

Ira Byock, MD, Director
Jeanne Sheils Twohig, MPA, Deputy Director
Promoting Excellence in End-of-Life Care

“MUCH KNOWLEDGE HAS ACCRUED ABOUT WHAT MAKES FOR GOOD PALLIATIVE CARE, AND NURSES HAVE BEEN IN THE FOREFRONT OF EFFORTS TO IMPROVE QUALITY OF LIFE FOR PATIENTS AND FAMILIES THROUGHOUT THE EXPERIENCE OF ILLNESS.”¹

BACKGROUND

As America moves into the 21st century, a new health care crisis surrounding how people die is occurring. In the beginning of the 20th century people died at an earlier age and did not enjoy the fruits of preventive care. By comparison, Americans now live longer creating a phenomenon known as the graying of America. In addition, Americans are living with many more chronic illnesses. The challenge of caring for the chronically and terminally ill aging population is increased by shortages of health care providers and, in particular, nurses. These changes have resulted in an erosion of the ability of health care providers to respond to the chronically and terminally ill on an individual and societal level.

The number of Americans living with advanced age and/or chronic illness continues to increase dramatically resulting in an increased need for specialized pain and symptom control. In addition, family members are assuming the majority of the care. A recent Gallup poll showed that 90 percent of Americans prefer to die in their own homes, while only 20 percent can realistically expect to achieve this goal.² The problem will only worsen in the near future. Many Americans can expect to enter a nursing home before they die.^{3,4} The challenge of caring for the chronically and terminally ill aging population is hindered by a lack of health care providers who have training and expertise in this area of practice.⁵ Therefore, there is a significant limitation in the ability to respond to the chronically and terminally ill on a societal level. Death and dying are no longer taboo topics in American society. However, access to high quality palliative care at the end of life is not universally

available, and the gains with regard to end-of-life care that have been made in the past decade are at risk given the significant growth of the elderly population and a shortage of expert practitioners.

Since many deficiencies in care reflect system problems, policymakers, consumer groups and purchasers of health care should support better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life.⁵

One demonstrated and cost effective response to this health care crisis is better utilization of advanced practice nurses (APNs).⁶⁻¹⁶ As members of the interdisciplinary team of health care providers, APNs have the knowledge and expertise to make substantial contributions to meeting the patient and family members' needs while maintaining social and fiscal accountability.

PALLIATIVE CARE

Palliative care refers to interdisciplinary team-based care for persons and family members experiencing life-threatening illness or injury, that addresses their physical, emotional, social and spiritual needs and seeks to improve quality of life across the illness/dying trajectory. The *Last Acts Precepts of Palliative Care* states, “Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity while remaining sensitive to the personal, cultural and religious values, beliefs and practices.”¹⁷

ADVANCED PRACTICE NURSING

The advanced practice registered nurse has a master's or doctoral degree in nursing, including a concentration in a specific area of nursing, as well as ongoing clinical experiences. Advanced practice registered nursing has evolved into the roles of Clinical Nurse Specialist (CNS), Nurse Practitioner (NP), Nurse Anesthetist (CRNA), and Nurse Midwife (CNM). APNs who specialize in palliative care are most often academically prepared to serve in the roles of CNS or NP. In addition to direct practice, other roles of the advanced practice nurse include: educator, consultant, researcher and leader.¹⁸

and to assume leadership roles in palliative care, both in practice and public policy arenas.²² Surveys indicate that the American public expresses a high level of trust in nurses and their ability to provide valuable life-affirming interventions even as death approaches.²³

Given that nurses are in every practice setting where patients are cared for and eventually die, advanced practice nurses are uniquely qualified and positioned to address the myriad needs facing individuals with life-limiting progressive illness. Clearly, collaboration with other providers (e.g.,

“NURSING AS A DISCIPLINE IS UNIQUELY QUALIFIED TO PROVIDE COMPREHENSIVE, EFFECTIVE, COMPASSIONATE AND COST-EFFECTIVE CARE...”

While many health care disciplines are concerned about improving care at the end of life, the nursing profession is particularly well suited to lead these efforts in view of the scope and standards of advanced practice. Nursing's social policy statement indicates that nurses “attend to the full range of human experiences and responses to health and illness without restriction to a problem-focused orientation; integrate objective data with knowledge gained from an understanding of the patient's subjective experience; apply scientific knowledge to the processes of diagnosis and treatment; and provide a caring relationship that facilitates health and healing.”¹⁹

Nursing as a discipline is uniquely qualified to provide comprehensive, effective, compassionate and cost-effective care and nurses serve as role models for members of other disciplines in promoting quality of life and quality of dying.^{20,21} With advanced knowledge of the physical, emotional, social and spiritual needs of seriously ill patients, APNs are prepared to model optimal care

physicians, social workers) must occur to attend to these vulnerable patients, but APNs have the knowledge and clinical judgment to prescribe, coordinate, implement and evaluate a comprehensive plan of care.

All constituencies interested in health care when faced with a life-limiting illness will hope to personally receive care that promotes the quality of every remaining day of life. Advanced practice nurses provide the expert care to make this hope a reality as they “Cure sometimes, relieve often, and comfort always.”²⁴

RECOMMENDATIONS

WE FIRMLY BELIEVE that Advanced Practice Nurses represent a valuable resource in national efforts to improve care and quality of life for Americans and their families living with advanced, life-limiting illness.

WE CALL ON LEADERS in the clinical professions, nursing educators, health service providers, health care payers, and public policy advocates to take the following actions:

- 1 PROFESSIONAL ASSOCIATIONS** in nursing, medicine, hospice and palliative care are called to engage in dialogue about the APN role and opportunities and strategies to advance it in palliative care.
- 2 NURSING EDUCATORS** must become knowledgeable about palliative care, and
 - Develop continuing education to prepare existing APNs in palliative care competencies for the care of patients and families experiencing a life-limiting illness;
 - Integrate core palliative care competencies into the education of all APN students, particularly those who will care for patients and families experiencing a life-limiting illness; and
 - Develop clinical tracks for APN students who intend to specialize in palliative care.
- 3 PAYERS OF HEALTH SERVICES** are called on to recognize the specialty of palliative care and provide APNs with adequate and consistent compensation that is commensurate with APN scope of practice, authority and responsibility, regardless of practice setting or specialty and subspecialty.
- 4 THE NATIONAL COUNCIL OF STATE BOARDS OF NURSING** and individual state boards of nursing are called on to work collaboratively to consistently recognize APN scopes of practice and privileges regardless of specialty and subspecialty.
- 5 HEALTH SYSTEMS OR HEALTH SERVICE PROVIDERS** are asked to develop or expand practice opportunities for APNs in all settings that care for patients who may experience a life-limiting illness.
- 6 ADVANCED PRACTICE NURSES** who practice in palliative care are called on to document and disseminate the outcomes of their practice experience and roles, engage in interdisciplinary research, and translate research findings into practice.

REFERENCES

1. Benoliel, J.Q., Foreword in B. R. Ferrell & N. Coyle (Eds.), *Textbook of Palliative Nursing*. 2001, New York: Oxford University Press.
2. *Brown University School of Medicine Facts on Dying: Policy relevant data on care at the end of life*. 2000, Center for Gerontology and Health Services Research. Available at www.chcr.brown.edu/dying/usa_statistics.htm.
3. Zerzan, J., Stearns, S., & Hanson, L., *Access to palliative care and hospice in nursing homes*. JAMA, 2000. 284(19): p. 2489-2494.
4. Hogan, C., Lunney, J., Gabel, J., & Lynn, J., *Medicare beneficiaries' costs of care in the last year of life*. Health Affairs, 2001. 20(4): p. 188-195.
5. Field, M.J., & Cassel, C. K. (Eds.), *Approaching death: Improving care at the end of life*. 1997, National Academy Press: Washington, D.C.
6. Coyle, N., *Supportive care program, pain service, Memorial Sloan-Kettering Cancer Center*. Supportive Care of Cancer, 1995. 3(3): p. 161-163.
7. Kuebler, K.K., *Interactive collaborative consultation model in end of life care*. Journal of Pain and Symptom Management, 2000. 20(3): p. 202-209.
8. Campbell, M.L., & Field, B. E., *Management of the patient with do not resuscitate status: Compassion and cost-containment*. Heart & Lung, 1991. 20: p. 345-348.
9. Campbell, M.L., *Program assessment through outcomes analysis: Efficacy of a comprehensive supportive care team for end-of-life care*. AACN Clinical Issues, 1996. 7(1): p. 159 -167.
10. Campbell, M.L., & Frank, R. R., *Experience with an end-of-life practice at a university hospital*. Critical Care Medicine, 1997. 25(1): p. 197-202.
11. Campbell, M.L., & Guzman, J. A., *Impact of a proactive approach to end-of-life care for critically ill medical intensive care patients*. SCCM abstract, 2000.
12. McCorkle, R., Benoliel, J. Q., Donaldson, G., Georgiadou, F., Moinpour, C., & Goodell, B., *A randomized clinical trial of home nursing care for lung cancer patients*. Cancer, 1989. 64: p. 1375-1382.
13. McCorkle, R., Robinson, L., Nuamah, I., Ley, E., & Benoliel, J. Q., *The effects of home nursing care for patients during terminal illness on the bereaved's psychological distress*. Nursing Research, 1998. 47(1): p. 2-10.
14. McCorkle, R., Strumpf, N. E., Nuamah, I. F., Adler, D., Cooley, M. E., & et al., *A specialized home care intervention improves survival among older post-surgical cancer patients*. Journal of the American Geriatrics Society, 2000. 48: p. 1707-1713.
15. Campbell, R.L., Banner, R., Konick-McMahan, J., & Naylor, M. D., *Discharge planning and home follow-up of the elderly patient with heart failure*. Nursing Clinics of North America, 1998. 33(3): p. 497-51.
16. Naylor, M.D., Bowles, K. H., & Brooten, D., *Patient problems and advanced practice nurse interventions during transitional care*. Public Health Nursing, 2000. 17(2): p. 94-102.
17. *Last Acts Precepts of Palliative Care*. 1997, Last Acts Palliative Care Task Force.
18. *American Nurses Association, Scope and Standards of Advanced Practice Registered Nursing*, American Nurses Association. 1995: Washington, D.C.
19. *American Nurses Association, Social Policy Statement*. 1995: Washington, D.C.
20. Matzo, M., & Sherman, D. W., *Palliative care nursing: Quality care at the end of life*. 2001, New York: Springer Publisher.
21. Ferrell, B.R., & Coyle, N., *Textbook of Palliative Nursing*. 2001, New York: Oxford University Press.
22. Krammer, M., Ring, A., Martinez, Jacobs, M., & Williams, M., *The nurse's role in interdisciplinary and palliative care*; in Palliative Care Nursing: Quality care to the end of life, M. Matzo & D. W. Sherman (Eds.), 2001, New York: Springer Publishers.
23. *Consumer Opinion about Nursing*. Available at <http://www.nurseweek.com/features/99-7/hpoll.html>, in *Sigma Theta Tau International & Nurseweek/Healthweek*. 1999.
24. Doyle, D., Hanks, G. W. C., & MacDonald, N. (Eds.), *Oxford Textbook of Palliative Medicine* (2nd ed.). 1997, Oxford, England: Oxford University Press.



PROMOTING EXCELLENCE IN END-OF-LIFE CARE

A NATIONAL PROGRAM OFFICE OF
THE ROBERT WOOD JOHNSON FOUNDATION

Practical Ethics Center
University of Montana
1000 East Beckwith Avenue
Missoula, MT 59812
406.243.6601 Phone
406.243-6633 Fax
excell@selway.umt.edu
www.promotingexcellence.org