



***Advanced Practice Nursing:
Pioneering Practices in Palliative Care***

PROMOTING EXCELLENCE IN END-OF-LIFE CARE
A NATIONAL PROGRAM OFFICE OF
THE ROBERT WOOD JOHNSON FOUNDATION

Completing the Picture of Excellence

In 1997, The Robert Wood Johnson Foundation launched a national program *Promoting Excellence in End-of-Life Care* with a mission of improving care and quality of life for dying Americans and their families. We soon realized that the metaphor of a jigsaw puzzle seemed apt in describing our efforts to expand access to services and improve quality of care in a wide range of settings and with diverse populations. No single approach would suffice—a variety of strategies, models of care, and stakeholders are necessary to successfully complete the picture. This monograph represents one aspect of our work and one piece of the puzzle of ensuring that the highest quality of care, including palliative care, is available to all seriously ill patients and their families.

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In July 2001, *Promoting Excellence in End-of-Life Care*, a national program office of The Robert Wood Johnson Foundation, convened a group of advanced practice nurses (APNs) to discuss the state of palliative care advanced practice nursing in the United States, to identify gaps in and barriers to that practice, and to develop strategies for the future. The report from this day-and-a-half-long meeting, *Pioneering Practices in Palliative Care*, has three objectives: to facilitate conversation among nursing leaders about how to improve the state of palliative care advanced practice nursing, to illustrate successful models of pioneers in advanced practice nursing and to promote the advanced practice nurse's role in providing palliative care.

Principles of Palliative Care

A primary tenet of palliative care is that clinical professionals be aware of and respect patients' treatment wishes. Although preferences vary according to race, ethnicity and religion, most Americans—more than 90 percent in a recent Gallup poll—wish to be in their own homes or in a homelike setting when they die. Unfortunately, barely 20 percent of Americans die at home.

Other principles of palliative care, such as attention to physical comfort and personal dignity, pertain regardless of where a dying

person resides. Certainly, the 80 percent of Americans who die in institutions need—and deserve—expert symptom management and attention to personal and interpersonal aspects of life closure. (See sidebar "What is Palliative Care?")

The Impact of an Aging Society

At the start of the 21st century, the oldest of America's 76 million baby boomers are in their mid 50s and the youngest are approaching age 40. As advances in medical technology

continue to extend life, these aging Americans will have to contend with the aches, pains and progressive disabilities of chronic illness. The need for specialized palliative care to improve comfort and quality of life for this population is great—and it is growing. Policymakers, payers and consumer groups must encourage the development and application of better tools and strategies for bringing palliative care to more Americans.

Nursing Leadership

By articulating and asserting their values and vision, nurses can positively influence public discourse and social policy on caring for the most ill, infirm and aged Americans. Nurses are present in every setting where Americans receive care. In many health care facilities, it is a nurse who sees and evaluates patients first. Even when a patient dies at home, a home health or hospice nurse has been overseeing the person's care.

Advanced practice nurses play a critical role in expanding access to services and improving quality of care for patients with advanced chronic illness. By facilitating coordination and maximizing continuity of care, APNs are not only particularly helpful to patients and families, but also highly valued by their clinical colleagues and administrators.

APNs: Improving Quality and Access to Palliative Care

In communities and health systems nationwide, APNs with specialized training and experience in palliative care are leading the effort to improve access, promote clinical excellence and improve cost effectiveness. In addition, advanced practice nurses are contributing to health services research in palliative care, oncology, neurology, critical care, surgery and pediatrics.

APNs: Valuable Members of Interdisciplinary Teams

Palliative care advanced practice nurses often can provide patient care and family support throughout the continuum of care and disease trajectory. Practicing as members of interdisciplinary teams, APNs work with:

- Patients and families: APNs use listening skills to learn the full spectrum of patient and family concerns and to serve as patient/family advocates.
- Physicians and the palliative care team: APNs contribute to diagnostic evaluations and treatment. They also model and mentor effective modes of caring.
- Facility administrators: APNs manage the delivery of valuable health care services at the point of patient contact. Working within institutions and communities, APNs reach those in need while managing resources in an efficient, cost-effective fashion.

What's Inside

This report provides a window into the practices of APNs who specialize in palliative care. The practice settings described span the spectrum from hospital-based to independent practice to academia. Most of the featured pioneering APNs work as part of an interdisciplinary clinical team; others work in private practice or as consultants to teams or physicians.

As this monograph illustrates, APNs specializing in palliative care effectively and compassionately address the needs of patients and families who are experiencing life-threatening illness. They exemplify both the science and art of nursing by coupling expert knowledge and clinical judgment with respect, dignity and care. By melding basic human values with the pragmatism needed to be effective in today's environment, APNs are an invaluable resource as we strive to care for our nation's ill, infirm and elderly.

What is Palliative Care?

Palliative care is an approach to care that addresses the patient's physical, emotional, social and spiritual needs and seeks to improve quality of life not only for the ill person, but also for his or her family. Palliative care is provided by interdisciplinary teams of professionals, often including physicians, nurses, social workers, chaplains or spiritual counselors, and other health care disciplines.

Advanced Practice Nursing: Pioneering Practices in Palliative Care



Meg Campbell, RN, MSN, FAAN

URBAN TRAUMA/ EMERGENCY CENTER

Palliative Care Service
Detroit Receiving Hospital
Detroit, Michigan

Detroit Receiving Hospital (DRH) has made remarkable strides in providing palliative care to its patients. Meg Campbell, a nurse practitioner who currently leads the DRH Palliative Care Service, began her career in critical care nursing in the early 1970s when the field was expanding rapidly. “We were learning how to keep people alive who would ordinarily die, but we didn’t know which patients would actually benefit from these procedures,” Campbell recalls. “Do not resuscitate (DNR) orders were rare at the time, and it was not unusual to resuscitate people again and again in hopes of bringing them back from the brink of death. Intuitively, we knew which patients would die, but we didn’t know what else to do.”

When the opportunity presented itself, Campbell accepted the challenge of providing palliative care to patients at DRH, which is an urban tertiary care center. “I knew it was what I wanted to do. I already had excellent communication skills and a critical care background,” she explains. The past 13 years have proven her right. Today, Campbell asserts, “Palliative care is the best work I’ve ever done.”

Palliative Care as a Subspecialty

In Michigan, APNs have considerable independence as care providers—including prescription-writing privileges. Although APNs have to work with a

physician to prescribe Class II medications, direct supervision is not needed. “We can provide what patients need at the time they need it. That makes all the difference in the APN’s role and in patient care,” Campbell explains.

DRH’s Palliative Care Service, which is integrated into the entire hospital, is considered a subspecialty. “I focus on patients who are not expected to survive their hospital stay,” says Campbell. “It doesn’t matter what disease or injury a patient is dying from or where in the hospital he or she is.”

Campbell intervenes when a patient has an uncertain or poor prognosis. Using predictor models, she assists the medical team in recognizing the patient’s prognosis and then identifies appropriate interventions. Campbell assesses the patient and explores the value of palliative care with the medical team. She also works cooperatively with the hospital’s pain service.

DRH serves mostly indigent patients who typically do not have a primary care provider. In most cases, there are no previously established physician/patient relationships. “In about 85 percent of cases, the attending physician and resident team sign off on the patient when we sign on,” Campbell explains. She provides a traditional consult service for the other 15 percent of patients whose physician and resident team wish to continue writing orders and directing care. Campbell’s Palliative Care Service is solely hospital based. A small number of patients, fewer than 10 percent, are discharged from the hospital to receive ongoing home-based or facility-based palliative care via hospice providers in the community.

Although Campbell does not have a standing palliative care team, she insists she has something even better. “I have access to anyone I need from the hospital or university,” she explains. “Unlike the hospice model in which team members are fixed, the hospital-based practice at Detroit Receiving is just me—but I can involve a chaplain, social worker, dietitian, psychologist, wound specialist or whomever the patient needs.”

Early hospital data showed that even though Campbell was seeing 40 percent of non-trauma patients, her interventions were coming later in the illness or injury course than optimal—this despite efforts to educate medical staff regarding the benefits of early palliative care. In recent years, however, Campbell has focused on finding cases rather than waiting for referrals. Before starting her case-finding effort, she was seeing 27 percent of patients who needed palliative care. Now, she sees nearly 100 percent of eligible patients.

Funded by Cost Savings

Campbell is a salaried employee of the hospital, which bills for patient care, but not specifically for Campbell’s services. Most patients are covered by Medicare or Medicaid. The hospital funds Campbell’s position because of the cost savings associated with avoiding unwanted and excessive treatment and unnecessary ICU days. Hospital data suggests that her interventions are saving, on average, five ICU days, and more than \$5,500 per patient.

Campbell is constantly collecting cost data on the effect of the Palliative Care Service. “I’ve kept a data set to justify the impact of the practice,” she says. “I can show how the number of consults impacts the institution’s bottom line.” Campbell notes that collecting data has preserved the program at times when budget cuts resulted in the elimination of other programs.

Education and Emulation

Campbell orients all new hospital nursing employees, introducing them to the Palliative Care Service, explaining what she does, and letting everyone know when and how to reach her. She also teaches nursing students at local colleges and universities and is an assistant professor of medicine at Wayne State School of Medicine in Detroit, where she participates in the ethics course taught to second-year medical students. In addition, Campbell presents cases at the department of internal medicine’s morning report, lectures in grand rounds, and conducts bedside teaching with nurses and physicians at every consult.

Campbell explains that other hospitals in Detroit and in Michigan have put similar programs in place. One of Campbell’s advanced practice nursing graduate students started a program at St. Joseph Mercy Hospital in Pontiac. The Fairview Health System in Minnesota is also emulating Campbell’s model.

Personal Reflection

In addition to collecting financial data, Campbell also assesses patient satisfaction. “The way I know it’s working is when the family can relax and even joke, when they can sit together and tell stories to one another,” she explains. “Some people laugh, others cry, but they no longer fret. They know what is going on and that the patient is comfortable. When that happens, I know all is going well.” Campbell also has one other measurement method: “I practice in the most litigious county in the state, and, despite the fact that so many of our patients die, we’ve never been sued.”

What is an Advanced Practice Nurse?

The advanced practice registered nurse has a master's or doctoral degree and has concentrated in a specific area of advanced practice nursing. She or he has had supervised clinical training in a specific area of practice at the graduate level as well as ongoing clinical experience. An advanced practice registered nurse may be a clinical nurse specialist (CNS), nurse practitioner (NP), nurse anesthetist (CRNA) or nurse midwife (CNM).

American Nurses Association. (1995a). Scope and Standards of Advanced Practice Registered Nursing. Washington, D.C.: American Nurses Association.



Constance M. Dahlin, RN, CS, MSN, ANP

ACUTE CARE TEACHING HOSPITAL Palliative Care Service Massachusetts General Hospital Boston, Massachusetts

Ten years ago, Massachusetts General Hospital (MGH) was not the place one would expect to find expert palliative care. MGH is a premier academic teaching hospital that prides itself on cutting-edge, life-saving medical treatments. Thanks in large part to the efforts of Constance Dahlin, however, palliative care has also been incorporated into MGH's daily activity.

Dahlin, a palliative care clinical nurse specialist and nurse practitioner, was one of the first members of the MGH palliative care team when it began in 1996. Today, in addition to Dahlin, the team includes two attending physicians, two physician fellows in palliative care training, a social worker, a bereavement/volunteer coordinator and an administrative assistant.

The MGH team provides a consulting service for patients who have life-threatening diagnoses

and are in need of symptom management, psychosocial support, grief and bereavement counseling, discharge planning, and/or long-term care planning. The patients served need not be actively dying. The goal is to alleviate suffering and develop a plan of care that enables patients to return to their own communities with hospice or home health services and ongoing support from the Palliative Care Service. "It's my job to make sure that each patient's needs are met at every stage of his or her illness," Dahlin explains.

Continuity of Care

In about 25 percent of cases of patients with life-limiting illness, the Palliative Care Service takes over primary care duties, often at the request of the physician. The team can devise plans of care and write medical orders. Dahlin and her colleagues often meet jointly with these patients and their physicians to ease any feelings the patient might have about being abandoned by his or her physician.

The continuity of care provided by the palliative care team is a key factor in its success. "We have a policy of continuing to check with patients and families," Dahlin explains. "The goal is for care to be as seamless as possible from hospital to home or hospice."

The team dedicates time and effort toward anticipating and preventing problems for patients and families and discussing issues such as advanced care planning, bereavement and other family issues. "We can take whatever time is necessary to deal with problems," says Dahlin. "We have expertise in pain and symptom control that can be very valuable to the patient. We help people get what they want," she continues. "We are their advocates."

The program was easily accepted because its champion, Andy Billings, MD, currently medical director of Palliative Care Service, had a relationship with the hospital as a primary care physician and hospice medical director. The program started slowly, but has grown, both in patient numbers and in case complexity. "We are building relationships, and people are judging us by the care we provide," says Dahlin, who strives

to have a presence on the floor. As Dahlin puts it, she does "curbside consults."

Dahlin is credentialed to provide consultations at the hospital, at an affiliated rehabilitation facility, in an independent oncology rehabilitation setting and at a nursing home. She bills under Medicare, Medicaid and third-party HMOs. Her salary is divided between the hospital budget and a physician's group.

Educational Interactions

The Palliative Care Service conducts weekly rounds on issues in end-of-life care and participates in weekly cancer-pain rounds, monthly ALS rounds and occasional oncology rounds. Dahlin and her team also hold weekly palliative care rounds on the oncology floor, psychosocial rounds and nursing rounds.

Dahlin serves as preceptor for graduate and undergraduate nursing students. She also runs two hospital workshops on pain management and palliative care, teaches continuing education courses for students and conducts in-service workshops as needed. "Every interaction is a chance for education," Dahlin explains, "and you can't take those opportunities lightly."

Formal family satisfaction surveys have demonstrated that the Palliative Care Service is appreciated. A clinician survey revealed that the service has been invaluable in difficult situations and has resulted in a quicker transition to less costly therapies. Dahlin's experience at MGH is testimony to the fact that APNs are an important link in providing care to patients across the continuum of care from the hospital to home.

Personal Reflection

"Being a nurse practitioner in a palliative care role is especially rewarding," Dahlin notes. "I'm able to work in an advanced practice capacity with all of the expertise that is involved and still use my nursing skills to be attentive to the human needs of my patients. I feel empowered to do whatever is necessary to help patients help themselves at a very critical time in their lives."

Roles of the Palliative Care Advanced Practice Nurse

In addition to direct involvement with dying patients, APNs in palliative care act in a variety of other roles. They can be:

- Designers of innovative practices for end-of-life care in a variety of settings.
- Educators of and consultants to other clinicians, medical residents, nursing students and other providers.
- Researchers who make important contributions to the professional literature and body of knowledge.
- Administrators within health care systems, institutions and clinical education programs.



Nessa Coyle, RN, MS, NP, FAAN

Most patients with progressive, debilitating cancer have palliative care needs. Some are at high risk for poorly controlled pain and other uncomfortable symptoms. Some also suffer heightened psychological distress when they are discharged back into the community. These patients and their families are referred to the Supportive Care Program for intensive follow-up. Patients with advanced disease may fit the hospice admission criteria. Those who do not, however, may benefit from a parallel system of care that focuses on life-prolonging therapy as well as aggressive palliative care. Both types of patients and their families are followed in the MSKCC Supportive Care Program.

Caring for Patients at Home

The purpose of the program is to provide expert palliative care to patients at home. Many program patients, though not all, live within the five boroughs of New York. Because most of the team's work is done via telephone, however, location is not an issue. The APN is available via telephone 24 hours a day.

The program provides a link between MSKCC and community health practitioners working with program patients. The program APN, with support from the MSKCC Pain and Palliative Care Service interdisciplinary team, facilitates continuity of care and, as requested, offers symptom control expertise to community clinicians.

The program also acts as an expert resource for patients, families and health professionals throughout the country who care for cancer patients with pain and other symptoms. In addition, it offers education and support for nurses and physicians who are increasingly faced with the care of chronically ill and dying cancer patients who have complex symptoms and family members who are exhausted and grieving.

A Collaborative Effort

The MSKCC Supportive Care Program is a collaborative effort among APNs, physicians and social workers. Consulting team members come from psychiatry, rehabilitation, nutrition services and chaplaincy. Other MSKCC resources are also

available to the program's APN coordinator and through her or him to the patient, family and community team.

APNs Nessa Coyle and Mary Laymen-Goldstein work with a caseload of 12 to 15 patients each. Their salaries are paid through the Department of Neurology and are considered part of MSKCC's clinical overhead. Each year, they make or receive approximately 3,200 telephone calls, 40 home visits, 200 outpatient clinic visits and 600 hospital visits. The small number of annual home visits is testimony to the fact that the Supportive Care Program works with the community home care team and is not intended to replace local clinical teams and practitioners.

The length of time that patients and families are followed varies from weeks to years. Intensity of involvement also varies, depending on need, from multiple telephone contacts in a day to weekly contact or even less. Although patients may be in a hospice program, they often require an ongoing relationship with the Supportive Care Program if their symptoms are particularly complex. Some patients may not meet hospice admission criteria but have palliative care needs, nonetheless. Others may decline to join a hospice program.

Personal Reflection

"This is a wonderful and personally enriching area to work in," Coyle says. "I am constantly learning from patients and their families. To work in this field, you need to have a good grounding in symptom management and the domains of suffering. You also need the ability to listen. Patients and their families are our constant teachers," Coyle continues. "Listen and you will learn what they need. They will also teach you about living and dying."

Palliative Care Certification

Certification in hospice and palliative nursing is offered at the generalist level through The National Board for Certification of Hospice and Palliative Nurses Association. An advanced practice palliative care certification examination is being developed through a partnership of the American Nurses Credentialing Center and the National Board of Hospice and Palliative Nurses Association. The examination will be available for nurse practitioners and clinical nurse specialists in spring 2003.

URBAN RESEARCH CANCER CENTER

Supportive Care Program
Pain and Palliative Care Service
Memorial Sloan-Kettering Cancer Center
New York, New York

The Supportive Care Program at Memorial Sloan-Kettering Cancer Center (MSKCC) bridges the gap between hospital and community care. It provides continuity of intensive palliative care for cancer patients and their families who are being followed by the hospital's Pain and Palliative Care Service and who are returning home. The program extends the team concept by bringing the expertise of a comprehensive cancer center, including a commitment to palliative care, into the community. There is no charge to patients or their families for this service.



Patricia Murphy, PhD, APN, FAAN

LARGE INNER-CITY HOSPITAL SERVING A DISADVANTAGED URBAN POPULATION

**University of Medicine and Dentistry of
New Jersey—University Hospital
New Jersey Medical School
Newark, New Jersey**

APN Patricia Murphy heads the University of Medicine and Dentistry of New Jersey—University Hospital's (UMDNJ) interdisciplinary End-of-Life Consultation Service. Murphy started the service in 1999. Prior to coming to UMDNJ, she worked at Beth Israel Medical Center in Newark, where she chaired the ethics committee.

Other members of the End-of-Life Consultation Service include a Baptist minister, two master's-prepared death and dying counselors, and an ethicist. A surgeon and an oncologist participate on an as-needed basis. Murphy sees patients and their families every day concerning pain, grief and ethical questions.

The End-of-Life Consultation Service is unlike many hospital palliative care services in that it embraces a broad range of services from middle-of-the-night acute bereavement support to complex ethics consultations regarding treatment decisions for patients who may have no burdensome symptoms. Murphy, who is EPEC trained (Education for Physicians on End-of-Life Care), is a salaried employee of the hospital. Clinical services provided by the End-of-Life Consultation Service are billed to third-party payers.

Palliation for Trauma Victims

The consultation service received a jump-start from a series of grants that permitted Murphy to hire staff. Later, Murphy and Ann Mosenthal, MD, a trauma surgeon, were awarded a joint Project on Death in America faculty scholar grant. Their project was to identify trauma patients who were actively dying and provide them with palliative care. Their success was startling. Word spread within the hospital and soon nurses, physicians and patients' families began to ask for the End-of-Life Consultation Service. "People started calling when they could see that we were making a difference," Murphy says.

Working with the Palliative Care and Pain Service at Beth Israel Medical Center, Murphy and Mosenthal developed standing orders for actively dying patients. University Hospital's Trauma Service incorporated the orders, and they are now accepted hospital-wide for all dying patients. In addition, Murphy regularly conducts pain and ICU rounds. "As residents rotate through the End-of-Life Consultation Service," Murphy notes, "they learn that there is a better way to care for patients near the end of life and their families."

Because the program has been developed with grant support, sustaining the team and its clinical services will be a challenge. In an inner-city hospital serving a large population of impoverished patients, the cost savings resulting from the team's interventions should more than pay for the program's costs. Murphy is collecting the data to prove this hypothesis. So far, anecdotal evidence indicates that the program is getting people out of the ICU more quickly, is resulting in the use of fewer resources and is decreasing the number of patients in nursing homes in a vegetative state.

Murphy believes that anyone with sufficient drive, a readiness to work long hours—at least in the beginning—and knowledge of pain management can put together a palliative care team and promote the use of standard order forms. She acknowledges, however, that much of her team's impact on the system is due to the commitment and tenacity of her colleagues.

Personal Reflection

"Many of the patients at our hospital are medically underserved," Murphy explains. "For some, our service is their first exposure to palliative care. Many people write to us about the excellent care they or their loved ones received here."

Paying for APN Services

As this monograph illustrates, APNs can receive several forms of reimbursement for their services.

Direct reimbursement for APN services can come from several sources. APNs can bill Medicare at 85 percent of the rate physician's receive. To be reimbursed, an advanced practice nurse must collaborate with a physician and be certified as an advanced practice nurse by a national organization. A master's degree will be required by 2003 to receive reimbursement from Medicare. APNs can bill Medicaid for reimbursement, but the rules and rates vary from state to state. Other third party payers, such as insurance companies, usually reimburse APNs for clinical care.

APNs are also often on salary in medical institutions that bill for APN-provided services. Furthermore, in a number of institutional and practice settings, particularly capitated or federally financed safety net health systems, APN's salaries can be financed through cost avoidance of unnecessary hospitalizations or ICU days or through improved system efficiency resulting from their involvement in palliative care.



Martha L. Henderson, MSN, MDiv, DrMin, GNP

A UNIVERSITY-AFFILIATED GERIATRIC PRACTICE

School of Nursing and School of Medicine
University of North Carolina–Chapel Hill
Chapel Hill, North Carolina

Martha Henderson practices as an adult nurse practitioner and geriatric nurse practitioner through the Program on Aging at the University of North Carolina–Chapel Hill (UNC). A self-proclaimed “end-of-life care facilitator,” she helps fill the health care and communication gaps often faced by the chronically ill elderly. Henderson is a Project on Death in America faculty scholar. Her special area of expertise is advanced care planning. Her doctoral dissertation, *Beyond the Living Will*, explores results from a study showing that discussing end-of-life preferences lowered death anxiety in a sample of retirement community elderly.

Generally, the patients Henderson serves have fallen through the cracks, being ineligible for home care and hospice, and have advanced

chronic illness, such as end-stage heart and lung disease, dementia or cancer. Because their prognosis and trajectory for dying is fairly uncertain, they may not meet hospice’s six-month criterion. In addition, many of Henderson’s patients do not see themselves as terminally ill. Henderson also cares for people whom home health won’t see because they can’t meet the strict criterion of being homebound.

Delivering the Basics

Henderson provides five basic services. She calls in professional colleagues as needed to ensure that these services are available:

- **Assessment:** Henderson assesses the patient’s function and the adequacy of current living arrangements, including caregiver support.
- **Symptom management:** Henderson does what is necessary to ensure that chronic illness is treated at the maximum level possible and/or that comfort care, including drug therapy, is

provided. She also asks patients what is most important to them and how they want to use their limited time and energy.

- **Advanced care planning:** Henderson defines advanced care planning as a “process in which people begin to think about their mortality, what’s important to them and how they want to die.” She helps her patients write an advanced care plan, including appointment of a surrogate decision maker and the completion of an advanced directive, if that is what they desire.
- **Emotional, social and spiritual counseling:** Henderson helps patients deal with their own grieving and letting go of life. She may treat depression or anxiety with medication and counseling. Henderson also helps people come to terms with dying, which often involves listening, praying and reading scripture. She may make a referral to a pastor, priest or rabbi to help the patient maximize his or her own resources for spiritual support.
- **Continuity, coordination and communication:** Henderson stays with a patient and family from admission until the patient dies. “This means that every time the patient changes settings, they have a familiar face—a care provider who knows them medically and personally,” she explains.

Referrals to Henderson come from hospice, primary care providers, friends, nursing colleagues and through UNC’s Program on Aging. The amount of care given depends on patient need. Some of Henderson’s patients are stable and require only monthly visits. When patients are unstable or actively dying, however, Henderson may see them frequently or may refer them for hospice care.

Henderson is supported by the UNC’s Department of Medicine, which donated 20 percent salary for her position to care for chronically ill adults who don’t qualify for hospice or home care but need additional assistance to improve their quality of life.

Although Henderson has had the financial support of the Program on Aging and the UNC Department of Medicine, the lack of full reimbursement for her time through Medicare Part B makes long-term support for her position an uncertainty. Currently, she receives reimbursement for about 50 percent of her time. Thus, some of her “behind the scenes” telephoning to family and physicians, work with the family and coordination of services is not reimbursed.

Focus on Education

Henderson speaks, consults and conducts workshops throughout the United States. She teaches physicians, nurses and other health professionals how to help their patients prepare for death. Her advanced care planning facilitator course is designed for those who want to learn how to talk to people about what they want at the end of life. She and her colleagues have developed a worksheet to guide an advanced care planning discussion in the primary care setting. She also consults with hospice providers. In addition, Henderson is helping to educate other nurse practitioners about end-of-life care through participation in palliative care efforts of the American Academy of Nursing and in her role as chair of the End-of-Life Care Task Force for the American College of Nurse Practitioners.

Personal Reflection

“I do everything possible to keep patients comfortable and help them fulfill some of their dreams,” she explains. “I try to help them find joy within the confines of their illness.”

“Our evidence of success is the satisfaction of patients and families,” Henderson says. “Each family completes an evaluation after the death of their loved one. These evaluations are always very good and show the family’s gratitude.” Physicians also seem satisfied with Henderson’s efforts to improve patient care. “As long as I keep communicating with doctors about important changes in their patients, they are always very appreciative of the care I provide,” she notes.



Kim Kuebler, MN, RN, ANP-CS

RURAL PRIMARY CARE

Adjuvant Therapies, Inc.
Lake, Michigan

Kim Kuebler started Adjuvant Therapies, Inc., as a community-based primary care practice with an emphasis on palliative care. Her practice illustrates the potential role for the advanced practice nurse in providing continuity and coordination of care for patients living with and dying from advanced illness. Kuebler is an adult nurse practitioner and clinical specialist in oncology who serves as a primary care provider for her patients. She focuses on integrating palliative care into traditional health services for the underserved, sparsely populated, rural community of Lake in central Michigan (population: approximately 25,000). Kuebler patterned her practice model after Great Britain's Macmillan nurses, who are trained to complement physicians and public health nurses in providing continuous, coordinated care for people with advanced, incurable illness and for their families.

Kuebler follows her patients throughout their illness, helping them and their families make the transition to palliative care as their disease progresses and the end of life nears. She provides case-managed care by accessing appropriate community and specialty physician referrals to meet individual patient and family needs. She also focuses on secondary prevention of problems to which patients with chronic illness are prone.

As a nurse practitioner, Kuebler performs comprehensive physical examinations, orders and interprets diagnostic tests and prescribes medications. Because APNs in Michigan cannot prescribe Class II medications, such as opioid analgesics, Kuebler has a collaborative practice arrangement with two internal medicine physicians who can prescribe appropriate pain medications based upon her assessment and recommendations.

Kuebler carries an average patient census of 350 active patients; approximately 45 to 50 are seen in their homes. Eighty-five percent of the care Kuebler provides is palliative in nature. "I follow patients back into their home setting," she explains, "making sure they have the services that they need, including physical, occupational or respiratory therapy, skilled nursing care, senior services and/or hospice care." Kuebler makes many weekend home visits to prevent crises and respond to exacerbations of pain and other symptoms.

In addition to her collaborative practice arrangement with the internal medicine physicians, Kuebler also works with a clinical psychologist and a massage therapist. When patients are referred to hospice, Kuebler directs their medical management and continues to see them until their death. She also attends hospice interdisciplinary team meetings. Kuebler bills under traditional codes and receives reimbursement from Medicare, Medicaid and third-party payers. She bills for her services as a nurse practitioner in private practice, independent from hospitals, clinics or long-term care facilities.

Getting Started

Kuebler says that starting her practice has not been without difficulties. "It's been hard," she reports. "At first, other providers resented a nurse practitioner working in the community. I struggled for hospital privileges and met constantly with the CEO and with local physicians."

During her three years of service, Kuebler has seen more than 2,000 patients. Some of her original patients are still alive and continue to

derive comfort from Kuebler's services. Patients who have died under her care have commonly been served by hospice for six to eight months, far exceeding the national average for hospice length of stay. "My patients are not abandoned. They continue to see me until the end," Kuebler explains.

"I started out as a hospice nurse," she continues. "I understand case management and make sure that my patients are not falling through the cracks, that all of their needs are addressed and that services are based upon individual preferences. My patients and their families are very satisfied. By making routine phone calls to my patients, I ensure that any emerging problems are caught early and managed."

Sharing the Knowledge and Experience

Kuebler opens her doors to undergraduate and graduate nursing students from all over the United States. To date, 10 graduate students have worked side by side with her for up to three days. She also takes two or three local associate-degree nursing students on home visits during each semester.

Recently, Kuebler was funded by the Michigan Department of Community Health to work in partnership with the Michigan Nurses Association to produce palliative care self-training products and a clinical consultation Web site. These resources will be integrated into six graduate nursing curricula in Michigan and within the Veterans Administration nationally.

Kuebler and her colleagues also published *End-of-Life Care Clinical Practice Guidelines* (W.B. Saunders), the first textbook of its kind to address evidenced-based clinical aspects of palliative care for the advanced practice nurse.

Kuebler believes that anyone can emulate her model. "I'm not creating any new reimbursement structure," she says. "I am using traditional reimbursement codes while demonstrating a specialty in palliative practice. I am able to provide continuity and coordinated care in a cost-effective fashion."

Personal Reflection

"Persevere" is the single most important piece of advice Kuebler offers to nurses interested in pursuing a career similar to hers. "What you have to offer is unique. It does make a difference and improves patient outcomes," she says.



Michelle A. Hobbs, RN, MS, CNP

RURAL PRIVATE PRACTICE

Palliative Care Concepts, Inc.
Greenville, Ohio

Michelle Hobbs, a family nurse practitioner, is president of Palliative Care Concepts, Inc., an independent practice headquartered in Greenville, Ohio, the county seat of rural Drake County (population: 53,309). In Ohio, nurse practitioners can provide comprehensive health assessments, diagnose and manage acute and chronic illnesses, order and interpret diagnostic studies, and formulate care plans to manage illness and promote wellness.

In her practice, Hobbs provides pain and symptom management, assists with advanced care planning, assesses emotional needs, offers psychosocial and spiritual support, and identifies and accesses community resources. She has prescriptive authority through a pilot project at Wright State University in Dayton, Ohio, and is required to practice within a collaborative agreement established with one or more physicians. "I've focused my practice on palliative care for patients of all ages and in all settings," explains Hobbs, who sees her patients wherever they are—at home, in a nursing home, in the hospital or in an assisted-living facility.

Hobbs is the only nurse practitioner on the medical staff at Wayne Hospital in Greenville, Ohio. Patients are referred to her by physicians, who consider her services an extension of the care they provide, or by nurses and social workers in hospitals and nursing homes. Patients also call her directly after hearing about her services from a friend or reading about her in the local newspaper.

Overcoming the Challenges

Hobbs overcame some major hurdles when she started her practice two years ago. “I was one of the first nurse practitioners in this county and the very first to start an independent practice,” she explains. “Many people were unfamiliar with nurse practitioners, and palliative care was not well understood.”

With the support of local physicians, Hobbs began to provide an additional service—a wellness program that helps patients newly diagnosed with chronic, potentially terminal illnesses stay as well as possible while living with progressive disease. Patients and caregivers in this program are educated about their specific disease condition, medications and plan of care. Patients also participate in advanced care planning to ensure that their wishes are always honored. In addition, Hobbs introduces patients and families to community resources that can assist with practical needs. She also conducts a Care for the Caregiver class, in which she teaches how to care for an ill loved one and offers practical advice to caregivers in dealing with their own psychosocial and spiritual concerns.

The majority of Hobbs’s patients reside in nursing homes. She has provided consultation in six area nursing homes to ensure that patients receive adequate pain and symptom management. She is now working with these nursing homes to implement a demonstration project designed to build palliative care teams and change policies and procedures to provide a full range of palliative care services.

Paying for Practice

After two years, Hobbs’s practice is self-supporting, sustained by reimbursements and fee-for-service revenues, and is not underwritten by any medical institution. She has her own Medicare and Medicaid provider numbers and bills patients or their third-party payers directly for consults and care. Some HMOs do not reimburse any nurse practitioner services, however Hobbs has found this exclusion to be rare.

Extending a Successful Approach Through Education and Service

Hobbs believes that nearly 100 percent of her patients experience some improvement in their symptoms. “My patients and families feel more in control in a very out-of-control situation,” she says. “In the past, patients have had to choose between aggressive curative treatment or

comfort-oriented care. Palliative care brings those two ends of the spectrum together, allowing patients to be comfortable from the time they are diagnosed with a potentially terminal illness through the moment of their death.”

Hobbs, who chairs the pain committee at Wayne Hospital, has presented many pain education seminars. She is also a member of the faculty at Wright State University, where she is exploring ways to weave palliative care into undergraduate and graduate nursing curricula. Hobbs has conducted research examining pain assessment and treatment in cognitively impaired elderly and has given a number of seminars in Ohio on this topic. She has also presented a Web-based teleconference for the Hospice and Palliative Nurses Association and serves as an expert on the association’s “Ask the Expert” Web page.

She believes the Wayne Hospital model is ideal for implementation in rural communities where no one health care organization or facility can support a full palliative care program. Palliative care services led by a nurse practitioner can be woven throughout the existing health care structure of a small community.

Personal Reflection

Hobbs advises nurses exploring APN practice of palliative care to “know you can make a huge difference in people’s lives. APNs have a significant body of knowledge, experience and expertise. Our autonomy allows us to care for patients and families in truly innovative ways and fill gaps in the current health care system.”



Jennifer Gentry, RN/C, MSN, APN

LONG-TERM CARE FACILITY

**Carver Living Center
Durham, North Carolina**

Jennifer Gentry uses her nurse practitioner training and specialization in palliative care to provide medical care for the residents of Carver Living Center (CLC), a 272-bed long-term care facility in Durham, North Carolina. One of the largest nursing homes in the state, CLC offers short-term rehabilitation, long-term care and hospice care. “Our motto is function and comfort,” Gentry explains. “In everything we do, we ask how it will benefit the patient—and how it will make the patient more comfortable or more functional.”

As a nurse practitioner in North Carolina, Gentry is able to act independently as an on-site primary care provider for facility residents. Rather than waiting for a patient’s doctor to visit or for a clinic appointment, Gentry can evaluate and treat a CLC patient with minimal delay. Often, problems that might have required emergency treatment and hospitalization are averted.

CLC’s progressive medical director, William F. Uthe, MD, has worked closely with Gentry to integrate palliative care into the normal flow of clinical care at the nursing home. Rarely does a week go by without a family meeting to discuss issues of palliative care and to determine what steps should be taken to ensure a resident’s comfort and continuing excellent care.

Careful Case Management

Case management begins the moment patients are admitted to the CLC. For new patients, Gentry performs the admission, takes the patient’s medical history, and writes orders for lab tests and for an initial plan of care. For existing patients, she examines, diagnoses and treats whatever medical problems occur. Part of her routine includes discussing patient preferences for care and advanced directives, either at the time of admission or shortly thereafter.

People are admitted to CLC from the hospital, from home and from hospice. At times, it is clear that the patient being admitted has only a short time to live. In these cases, Gentry convenes a meeting with the physician and family. “I sit down with family and review the patient’s advanced directive,” she explains. “We talk about what to expect. Everyone is different, and taking individual differences into consideration is one of the secrets to success.”

Financial Viability

Carver Living Center bills Medicare, Medicaid, private insurance and patients for Gentry’s acute care services. Her salary is covered by reimbursement, thus allowing the facility to recoup the expense of a full-time care provider. Gentry has collected data showing that CLC nursing home residents make significantly fewer trips to the hospital emergency room than average, resulting in lower patient costs and a less stressful atmosphere in the facility. In addition, hospice referrals have tripled since Gentry joined the facility.

Collaboration at Work

The philosophy of palliative care is implemented at CLC through the day-to-day, hands-on care given by attending physicians, a second nurse practitioner, a physician assistant and a social worker. In addition, Gentry has worked hard to develop collaborative relationships with area medical specialists to improve access to services for CLC residents. For instance, a local neurologist now holds a clinic at the facility six times a year.

Gentry frequently consults with the CLC nurses at the bedside. “I validate their nursing skills and teach them techniques of palliative assessment and care,” she explains. She also conducts in-service training for staff, teaches nurse practitioners and resident physicians, and serves as a mentor for nurse practitioner students from University of North Carolina–Chapel Hill and from Duke University.

Personal Reflection

CLC’s success story is traveling by word of mouth. “Several times a year I get a phone call from a nursing home administrator who wants to learn how we improve people’s lives,” Gentry says. “Our model is self-sustaining and relatively easy to implement with the right kind of leadership and support.”



Denice Kopcha Sheehan, RN, MSN

GRADUATE EDUCATION IN PALLIATIVE CARE

Palliative Care Program
Ursuline College
The Breen School of Nursing
Pepper Pike, Ohio

Denice Sheehan, a clinical nurse specialist, coordinates the palliative care track in the master of science in nursing program at The Breen School of Nursing at Ursuline College in Pepper Pike, Ohio. This graduate program is the first in the United States to prepare clinical nurse specialists in palliative care. The first course was offered during the summer of 1997.

Sheehan based the Ursuline program on a national and regional needs survey indicating that palliative care nursing experts supported the need for graduate education in palliative care. This support was echoed by Ursuline College nursing alumnae and Cleveland nursing leaders. The program started with nine students and now enrolls 23 in the palliative care track and post-master's certificate program.

Building a Partnership

Sheehan, who has extensive clinical experience in oncology and hospice, decided that palliative care needed to be included in the graduate nursing curriculum. "We needed a partnership among students, clinical agencies and faculty," she explains.

Ursuline students learn three ways: classroom work, interaction with experienced nurses and an open-door faculty policy. "These three elements plus reflection and contemplation are the strengths of our program," Sheehan explains. "Our educational program is based on values. Students learn about themselves first by looking

at their own values. Then they are able to listen and learn about patient values and provide care based on patient and family needs."

Communication is another program focus. Students learn how to talk with someone who is dying. "Over time," Sheehan says, "they come to see dying as a potentially rich experience and gain perspective on their own beliefs on the meaning of life and their own direction in life."

Instruction includes lectures from invited experts and reviews of the current literature on best practices. This approach ensures that graduates are familiar with palliative care excellence and are well positioned to contribute to the palliative care body of knowledge. Each of the clinical nurse specialist students also completes a practicum. Many spend hours at the Cleveland Clinic's Harry R. Horvitz Center for Palliative Medicine where they work with the inpatient and outpatient clinical teams. "They are very involved and part of the interdisciplinary team," Sheehan explains. Students often spend time at the Hospice of the Western Reserve's Hospice House where they work with advanced practice palliative care nurses, physicians and other providers. Students also work at a variety of other clinical sites, where they learn from professionals who provide grief and bereavement services.

Graduates in Demand

Student and preceptor evaluations are very positive. They are used to reinforce the strengths of the curriculum and seek direction for improvement. Program graduates are in demand by clinical agencies and physicians. "More and more health care professionals nationwide are calling and asking when we will graduate the next class," Sheehan says. "Of the seven nurses who have graduated so far, four are directly involved in the provision of palliative care."

Personal Reflection

Prior to establishing this graduate program, Sheehan's research showed that there were no programs that incorporated palliative care in Ohio or the nation. "I decided that palliative care needed to be included in the curriculum and that it needed to be a partnership between students, clinical agencies and faculty. The education we are providing nursing students is paving the way to improve the ability of medical institutions and communities to care for people with life threatening illnesses and their families."



Deborah Witt Sherman, PhD, APRN, ANP, BC, FAAN

PALLIATIVE CARE NURSE PRACTITIONER PROGRAM

New York University, Division of Nursing
New York, New York

Deborah Witt Sherman coordinates the first palliative care nurse practitioner program in the country. New York University's master's program and post-master's certificate program prepare nurse practitioners to provide comprehensive and compassionate care to individuals and families who are living with or dying from an incurable, progressive illness.

Building on a Solid Core

The palliative care curriculum builds upon the core of the master's program in nursing, which focuses on theory, research, critical thinking, knowledge development, health care policy and leadership. In addition to advanced science courses in pathophysiology, pharmacotherapeutics and advanced physical assessment, students take role development courses and five specialized palliative care courses, totaling 710 precepted clinical hours. Palliative care course topics include loss, grief, death and bereavement; management of pain and suffering; end-of-life care; symptom management; and nursing leadership in palliative care.

The program also builds upon a common trait of nurses—a deeply rooted humanitarian concern. "Our program allows nurses to acknowledge their human compassion as well as their expert knowledge and advanced practice skills in palliative nursing," Sherman explains. "This quality is what makes the program a very different experience."

Each student receives both inpatient hospital and hospice palliative care experience. Students select where they receive this experience from a list of clinical sites that meet the student's educational goals.

Sherman collects evaluation data at the end of each semester from each of her students. Students evaluate their courses, faculty, precep-

tors and clinical sites. Program preceptors also evaluate the curriculum and their students. This information is used to strengthen the curriculum and to identify program and course competencies. Since the inception of the master's program in the fall of 1998, 15 students have graduated and are demonstrating nursing leadership in palliative care. Currently there are 34 master's and post-master's students in the program.

Making a Difference

As a member of the nursing faculty for a newly funded interdisciplinary palliative care fellowship program at the Veterans Administration Hospital in the Bronx, Sherman and her colleagues are developing an interdisciplinary palliative care curriculum for physicians and a master's-prepared curriculum for nurses and social workers. These interdisciplinary initiatives emphasize the value of collaborative practice in ensuring quality palliative care.

"As a cutting-edge specialty," Sherman notes, "palliative care is well-suited for the advanced practice nurse who wants to make a difference in the lives of patients and families who are living with and dying from incurable, progressive illness. It is an incredible opportunity to care for individuals at a very critical time in their lives, a time when they are extremely vulnerable and need expert nursing care. Advanced practice nurses," she continues, "can assist patients and families in achieving growth, well-being and quality of life throughout the illness trajectory, even as death approaches."

Sherman believes that New York University's advanced practice program in palliative care nursing can be emulated and, in fact, must be if palliative care is going to be recognized as a nursing specialty by state boards of nursing. She encourages other graduate programs in nursing to consider developing a palliative care master's program, a post-master's certificate program in palliative care and/or a dual concentration for students in adult nurse practitioner or geriatric nurse practitioner programs.

Personal Reflection

Sherman herself continues to follow her calling. She advises aspiring students: "Follow your heart. The answer is inside you. If you are always drawn to people with incurable illness and feel compelled to offer them support, that's a message. Listen to what your heart is saying."

FUTURE DIRECTIONS

As these brief profiles reveal, APNs represent a valuable resource for responding to the needs of seriously ill Americans and their families—in a wide variety of geographic and clinical settings and in difficult demographic and sociologic circumstances. All the APNs profiled here are pioneers in overcoming barriers and creating viable and sustainable practices. The clinical expertise and the caring capacity of advanced practice nurses should not go untapped as the number of elderly people grows and the medical system attempts to care for them.

Advanced practice nursing in palliative care offers an exciting career opportunity that can help attract a new generation of men and women to the field of nursing and the proud profession of caring. Currently, however, APNs face challenges in training and licensure, and they may encounter regulatory and reimbursement barriers. With the development of generalist and advanced practice credentialing examinations and the creation of undergraduate and graduate advanced practice programs in palliative care nursing, the time has come for palliative care nursing to be recognized as a specialty in all states. With this recognition, the dream of making effective and compassionate care available for seriously ill and dying patients and families will be one step closer to becoming a reality.



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