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# Advancing the Psychosocial Care of Patients With Cancer at Life's End: A Global Nursing Response

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Cancer remains a leading cause of death in both highly developed nations faced with an ever-aging population and in poor, developing nations that struggle with minimal healthcare resources for vast populations. In many nations, concurrent illnesses such as malaria, tuberculosis, and AIDS impact cancer care and the high mortality rates are accompanied by immense suffering due to factors such as lack of opioid availability and limited access to hospice or palliative care services.

In the United States, 570,000 people die of cancer annually and, worldwide, about 7.6 million people will die of cancer in 2011 (Jemal et al., 2011; Siegel, Ward, Brawley, & Jemal, 2011). For each of these people, the final chapter of their life can be not only a time of grief or suffering, but also an opportunity for profound healing, comfort, and growth. This opportunity is made possible by the expert psychosocial and physical care provided by compassionate and competent oncology nurses worldwide.

## Elements of Nursing Care for Dying Patients

Palliative care has emerged worldwide based on the efforts of hospice to transform the culture of dying. The modern hospice movement from the 1970s to the present has advanced attention to physical, psychosocial, and spiritual care. Although there is tremendous diversity in nursing practice and resources worldwide, there are also many unifying elements that characterize nursing contributions to improve psychosocial care of patients with advanced disease and those who are dying.

The five elements I have observed over my 34 years in oncology nursing include

- Challenging the paradigm of care
- Creating expertise and knowledge in palliative care

- Fostering nursing presence
- Expert attention to the body and relief of symptoms
- A vision of the end of life as a spiritual experience.

I have identified these essential elements through observation of nurses throughout the world who we have come to know through our End-of-Life Nursing Education Consortium (ELNEC) project. ELNEC launched its first palliative care training program in 2001 and has since prepared over 12,500 nurses to serve as ELNEC trainers in all 50 U.S. states and now in 69 countries (American Association of Colleges of Nursing, 2011; Ferrell, Virani, Paice, Coyle, & Coyne, 2010; Malloy et al., 2011; Paice, Ferrell, Coyle, Coyne, & Callaway, 2007; Paice, Ferrell, Coyle, Coyne, & Smith, 2010). From Japan to Tajikistan, from Kenya to Russia, Romania to South Korea, nurses around the globe are improving the care of people with cancer at the end of life. Their work is a testament to our pioneers, such as Mara Mogensen Flaherty, and dedication to psychosocial care at this enormously important time of life.

## Challenging the Paradigm of Care

Nurses have contributed greatly to psychosocial care by challenging existing paradigms of care. Oncology has evolved as a specialty with a focus on extending life or curing disease despite the reality of the high prevalence of advanced disease and deaths from cancer. Bringing attention to psychosocial needs requires challenging existing values, beliefs, and systems of care.

An excellent example of nurses challenging existing paradigms of care is within the Veterans Administration (VA) hospitals in the United States. The VA has made a major commitment to advancing palliative care and nurses have been at the forefront of these efforts. These VA nurses have challenged the practice of hospital deaths being hidden or silenced, with patients who die

briskly removed to the morgue covered within a veil of failure. Instead, a veteran's death within the hospital is seen as an opportunity to honor and celebrate a life with palliative care provided and respect for the body after death. Rituals such as draping the body with a flag and an announcement over the hospital audio system that a veteran's life has ended offers visitors and other patients the opportunity to join in the recognition of a life ending.

Lt. Commander Carma Erickson-Hurt, RN, MSN, OCN®, is a retired Navy nurse who has led such efforts in the U.S. and now around the world. She challenged paradigms of care and was an early voice for palliative care for veterans and active duty military personnel. Another VA nurse who has led efforts to challenge the existing paradigm of end-of-life care is Deborah Grassman, MSN, RN, NP. Deborah's book, *Peace at Last*, tells stories of last battles of "wounded warriors" (Grassman, 2007). Deborah is changing the paradigm of care by changing cultural values and beliefs about the deaths of veterans. Her voice is a strong cry for improved care.

The VA has responded to the ever-growing demands of the aging population and they have committed to palliative care education for their staff. Michelle Gabriel, RN, MS, ACHPN, who is former president of the Bay Area Oncology Nursing Society Chapter in San Francisco, has been the leader of a project to implement ELNEC education in VA hospitals throughout the U.S. Each of these three expert oncology nurses in VA hospitals is changing the paradigm of care.

Over the past 40 years, nurses have changed cultures of care through serving as the firsthand witnesses of patients facing the end of life. In 1996, pioneering oncology nurses Richard Steeves, RN, FNP, PhD, and David Kahn, PhD, RN, wrote about the role of nurses as witnesses and moral agents. They defined this role to include firsthand observation of suffering and providing a voice, providing ceremonial roles and rituals, being expert witnesses to suffering, and being visionary. To be visionary requires not only that we identify inadequate care but, rather, that we can imagine what excellent care would be like (Kahn & Steeves, 1996).

## Creating Expertise and Knowledge in Palliative Care

A mantra we have used in our ELNEC work is that "nurses cannot practice what they do not know." The ELNEC project began in 2000, with the first course held in January 2001. Over the past 10 years, ELNEC has hosted 85 training programs with over 12,500 in attendance. The courses are Train the Trainer, with the purpose of preparing nurses to train other nurses and to be dedicated to improved care. ELNEC has trained nurses from 69 countries across six continents. The content areas include

many aspects of psychosocial care, such as grief, communication, cultural aspects of care, ethics, and final hours.

Our experience over this past decade and 69 countries has been that nurses across the globe are eager to advance their skills to care for patients facing late-stage disease and those at the end of life. Enhancing knowledge and skills of nurses empowers them to be stronger advocates for those they serve. In many countries, nurses are undervalued, seriously underpaid, and their voices are not heard. Yet education and mentorship can make an enormous impact on their practice.

Since its inception, the ELNEC project has been coordinated by an expert oncology nurse, Rose Virani, RN, MHA, OCN®, FPCN. Rose has led the curriculum development of ELNEC, including the Core, Pediatric, Geriatric, Critical Care, Oncology, Graduate Education, and Veterans versions. Rose's skills as an oncology educator have provided training materials and assembled the evidence for thousands of nurses around the world to be effective change agents.

## Fostering Nursing Presence

The science of palliative care nursing and meeting the psychosocial needs of patients with cancer in palliative care is fostered by knowledge, but the art of palliative nursing is lived through nursing presence. As oncology has emerged as a complex specialty involving highly technological diagnostics and treatment regimens, oncology care can become protocol driven and impersonal. Yet the urgent need of patients and families facing cancer and death is for humanized, deeply personal care, which is contingent on nursing presence.

Expert oncology nurses know that, through their presence, suffering is diminished and the distress of psychological responses to life-threatening disease is heard. Teaching nursing presence, active listening, non-abandonment, and skillful communication is not easy; it is fostered through mentorship and by the art of nursing, which begins by recognizing the therapeutic effect of presence and the sacred nature of the nurse/patient relationship in oncology.

At the City of Hope National Medical Center in Los Angeles, CA, we are conducting a Program Project on Palliative Care for Quality of Life and Symptom Concerns in Lung Cancer. This project applies our model of quality of life to the lung cancer population, a group of patients often overwhelmed by advanced disease and the enormity of physical, psychological, social, and spiritual needs. The first phase of the research has documented many needs for improvement, including numerous physical symptoms and psychosocial concerns such as anxiety, depression, distress, and uncertainty.

The intervention phase of this research uses oncology nurses who guide an interdisciplinary team effort to proactively respond to the needs of patients with

lung cancer and a four-part teaching exercise in which these nurses address physical, psychological, social, and spiritual concerns. These nurses work closely with the patient's medical team, including the nurse practitioners and medical oncologists directing the lung cancer treatment (see Figure 1).

Cindy Kelly, RN, MSN, NP, is a nurse practitioner providing much of the care to these patients. At a recent meeting of this Program Project, each team member (which included pulmonary rehabilitation, nutrition, chaplaincy, medical oncology, thoracic surgery, social work, and several other departments) was asked to describe what they do to contribute to the care of patients with lung cancer. Cindy identified her commitment to each patient as she enters the clinic room and closes the door to what will become a brief clinic encounter in which she must assess the patient and coordinate highly complex care, often as the patient faces enormous burdens and a declining trajectory. But Cindy's vision of her real contribution was to be "fully present" to each patient in this encounter. Her role is a model for oncology nurses, exemplifying that we must be self-aware, whole, intact professionals and to be fully present for patients with cancer.

At an ELNEC course, nurses were asked to write essays about "What they did to relieve suffering." One such essay was submitted and, in response to the question, the nurse had written in large bold letters at the top of the page "I show up." Her essay shared the following.

Sometimes we can only witness. We cannot fix or do the work of creating meaning. This family responds to support, to ideas, to reframing, but ultimately they have to wrestle with the guilt themselves. We can provide a container, a holding environment of safety so they don't have to do this in isolation. We can keep showing up, even when it's messy and ragged and uncomfortable.



Note. Pictured, from left, Tami Borneman, MSN, CNS, FPCN, Catherine Del Ferraro, MSN, Ed, PHN, CCRP, Becky Fujinami, RN, CCM, OCN®, and Anna Cathy Williams, RN, BSN, PHN

**Figure 1. City of Hope Lung Cancer Program Project Research Nurses**

These elements of psychosocial care and nursing presence are of great value in the field of pediatric oncology. Nurses must be fully present to children and families living with cancer. The decline and death of a child requires exceptional nursing presence to sustain families facing pediatric cancer. Wolterstorff (1987) wrote of his experience as a bereaved father, admonishing professionals of the need for their presence.

Death is awful, demonic. If you think your task as comforter is to tell me that really, all things considered, it's not so bad, you do not sit with me in my grief but place yourself off in the distance away from me. Over there, you are of no help. What I need to hear from you is that you recognize how painful it is. I need to hear from you that you are with me in my desperation. To comfort me, you have to come close. Come sit beside me on my mourning bench (p. 36).

## Expert Attention to the Body and Relief of Symptoms

As nursing students in our first days of clinical practicum, we often are assigned our first task of performing a bed bath. This assignment is often conceived as the most basic of procedures, "low tech," and requiring little professional skill. However, nurses caring for patients at the end of life know that this skill learned in our first week of clinical practice is an exceedingly important task and one offering comfort, human connection, and true healing, even in the hours before death. Attention to the body and relief of symptoms is paramount in palliative care. Nurses have pioneered efforts in this area and modeled excellence in assessment and relief of symptoms. One exemplar is Patrick J. Coyne, MSN, APRN, FAAN, at Massey Cancer Center/Virginia Commonwealth University. Patrick has led his center in creating a model of inpatient palliative care and consultation service. Their palliative care leadership center has trained hundreds of other hospitals (see Figure 2). He has traveled throughout the world with ELNEC training to areas such as Kenya, Tajikistan, Kazakhstan, and many other countries to teach nurses and physicians about symptom management (Coyne et al., 2007; Virginia Commonwealth University, n.d.).

Another model nurse who is making a profound difference in the world is Joyce Marete, KRCHN, DIPHEd. Joyce is a nurse from Kenya working in hospice. She is a pioneer nurse, changing the face of dying in rural Africa (Marete, 2010). I met Joyce a few years ago when I was asked to be her mentor as she embarked on doing the first nursing research in her country. Joyce wanted to improve wound care of her dying patients. She knew that research could change practice.

In 2008, I had the opportunity to travel to Kenya with an ELNEC team (see Figure 3) to help Joyce to train hundreds of nurses and physicians in palliative care. Following this



Note. Bottom row, from left, Patrick J. Coyne, MSN, APRN, FAAN, Sree Battu, MD, Shaun Dela Cruz, Eloise Coyne, and Deena Bugge, RN, CHPN. Top row, from left, Barton Bobb, MSN, FNP-BC, ACHPN, Hemant "Monty" Murthy, MD, Barbara Geer, William Tatu DPT, Meera Pahuja, MD, Timothy Ford, MA, MS, CT, and Thomas J. Smith, MD, FACP

**Figure 2. The Thomas Palliative Care Program Team at Virginia Commonwealth University Health System**

visit, Joyce decided to leave the major city of Nairobi to return to her small village of Nanyuki. Joyce wrote to me to describe her first home visit back in her village.

My first home visit to a patient. It was a bright day and the sun was scorching hot. I set out to see our first patient accompanied by a volunteer who could also assist me with communicating with the patient because of language barrier. It was a 3 km walk distant. My first challenge was on the way my right shoe got torn and separated from its sole. I resolved to continue walking bare feet the rest of the journey and finally got to the patients home. I found the patient in the company of her family (granddaughters and a number of great grandchildren). It was midday and the family was having their meal of boiled dry maize that was very little and was clearly not enough for all of them. The patient who also blind was in a lot of pain and my next dilemma was how was I going to give the patient pain medicine in a almost empty stomach beside the counseling I gave to offer psychological support. I managed to leave the patient and the relative a bit more comfortable and as I left I resolved to think of more other ways to relieve pain and suffering to the patients here. This experience was an eye opener for us at LPCC as we get ready for the challenges ahead of us.

Joyce provides care which tends to the whole person. Her presence, skill, knowledge, and compassion transform the way people are dying.

## A Vision of the End of Life as a Spiritual Experience

Our technology-driven healthcare culture has created a belief that death is equivalent to failure and is only a physiologic experience. Nurses are changing

the paradigm of care as they create an alternate vision that the end of life is a spiritual experience. The end of life represents a time of healing, forgiveness, love, and growth.

At one of our earliest ELNEC courses, a group of nurses shared that their hospital was located next to a church and that each time a birth occurred in the hospital, the church would be called to ring the chimes. Staff, patients, and visitors then hear the chimes and stop to realize that a sacred event has happened in the birth of a child. The nurses returned from their ELNEC training and implemented a practice in which the church's chimes also ring a different tone when a patient dies, to signify this equally sacred moment of the ending of a life. In this way, lives are celebrated and deaths are honored rather than hidden or seen only as failures.

A nurse who lives a vision of the end of life as a spiritual experience is Carol Franko, RN, CHPN. Carol is a nurse employed by the Hawaii State Department of Health to direct health services at Kalaupapa, which is better known as the leprosy colony on the island of Molokai. Carol directs all health care for the remaining 18 people at Kalaupapa. The island of Molokai has a legacy of great suffering and death. From the mid-1800s to the mid-1900s, people with Hansen disease (leprosy) were forcefully removed from their communities and sent to Molokai. As ship captains feared getting close to the island, the people were often thrown overboard and had to swim to safety, only then to find a community ill prepared to care for them (VisitMolokai.com, 2011).

Kalaupapa was transformed by Father Damien and Sister Marianne, who came to Molokai to create health services, schools, churches, and to create a culture of respect. Over 8,000 people died on Molokai. Once Hansen disease could be successfully treated in the mid-1950s and patients were given the option of leaving the settlement, many opted to stay since Molokai was the only home they knew. These people now live long lives dying of cancer and other diseases. Carol and her colleagues



Note. From left, Thomas J. Smith, MD, FACP, Betty Ferrell, PhD, MA, FAAN, FPCN, CHPN, Judith Paice, RN, PhD, FAAN, Nessa Coyle, NP, PhD, and Patrick J. Coyne, MSN, APRN, FAAN

**Figure 3. End-of-Life Nursing Education Consortium Project International Course Faculty**

deliver care which recognizes these lives and the need for care which is respectful of their lives. As Carol and her colleagues have shared through personal communication, "The legacy of Molokai began as one of indignity. We have an opportunity to end the legacy with dignity."

## Fundamentals of Reform

There is much current attention to reform in health care. This reform is generally viewed only as revising mechanisms of payment. Dan Sulmasy, OFM, MD, PhD, a physician and priest, has written of the reform needed at the fundamental level of reimagining what health care should be. We need a reform of our systems that better embraces the complex needs of particular importance for the dying patients. In Sulmasy (2006), Dan wrote

Under this new medical covenant, a spiritual-scientific practitioner would affirm that the transcendent is made manifest at the edge of the surgeon's knife, at the tips of the palpating fingers of the pediatrician, in the firm handshake of the internist, in the birth of the child whose unwed mother has AIDS, in the tears of the woman who feels a hard lump in her one remaining breast, and in the vacant stare of the elderly man with dementia. A spiritual-scientific practitioner would affirm that the transcendent is there when disease and suffering are recognized together, when the hand that performs the spinal tap distills compassion into the needle's point, the objectivity of science with the subjectivity of God's healing will; the particularity of the case at hand with the universality of a profession under oath; the finitude of the moment and the infinity of a life lived in the service of love. Thus might the clinic be reborn (p. 213).

## Summary

Oncology nurses throughout the world are serving as models for psychosocial care at the end of life (Coyle, 2010; Coyne et al., 2007; Ferrell & Coyle, 2008; Grassman, 2007; Kahn, & Steeves, 1996; Malloy et al., 2011; Marete, 2010; Sulmasy, 2006; Virginia Commonwealth

University, n.d.; VisitMolokai.com, 2011; Wolterstorff, 1987). Though their practice, suffering is relieved.

Roshi Joan Halifex, a Zen Buddhist teacher and priest, wrote in 2011 of the nature of our work.

As caregivers, we encounter many, as Pasternak notes, who trigger those cracks in our heart and open us once again to suffering. Our work as caregivers of those who are dying is never to deny the truth and presence of suffering, impermanence, and death. As we are touched by these realities of existence, we realize that compassion is a moral, social, psychological, and spiritual imperative. But to do this work, we need to focus attention on our own spiritual resources to support our work. This is a profound path for those who care for the dying. It is the path that the great healers and teachers of the past have walked. And it is a path of sanity that clinicians and caregivers can discover, day after day, as they care for the dying. It is also beneath the feet of every human being. Fortunately, we live in a time when science is validating what humans have known throughout the ages: that compassion is not a luxury; it is a necessity for our well-being, resilience, and survival. May we see into the life of things, and may we have the courage to actualize compassion in our lives for the benefit of all those who suffer (p. 152).

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