



DNA

Reporter

The Official Publication of the Delaware Nurses Association

Online Supplement Edition of the Reporter

Hospice's Role as a Solution to Health Care Reform

by Susan Lloyd

For the last 22 years Susan has been serving as President and Chief Executive Officer for Delaware Hospice, Inc. Delaware Hospice is a community based not-for-profit hospice organization serving the State of Delaware and surrounding counties of Pennsylvania through three centrally located offices.



Susan Lloyd

Susan is a graduate of Bloomsburg University of Pennsylvania where she earned a Bachelor's of Science Degree in Nursing. She also holds a Master's Degree in Nursing Administration from Villanova University.

Susan has been an active member of the Delaware Cancer Consortium and the Delaware End of Life Coalition. She is past president of the Delaware Association of Home and Community Care and the Delaware HIV Consortium. Over the last several years she has been a member of NHPCO Public Policy Committee. Susan is also a Board member for NHPCO's Alliance for Care at the End of Life and most recently was elected as the Northeast Geographic Area Director on the NHPCO Board of Directors.

Susan Lloyd can be reached by email at sllloyd@delawarehospice.org or at her office at 302-478-5707.

As health care reform continues to be discussed, hospice providers have been provided a national platform to advocate for hospice care to be part of the solution.

Key terms in all versions of health care reform proposals include: choice, quality of care, reduction of health care costs. All of these are consistent with the realities of hospice care.

The decision whether or not to choose hospice care is essentially a decision to pursue care to cure an illness—even when cure is unlikely—or to experience the quality of life achieved with symptom

management through the final stages of life. In the best of circumstances, this decision is a difficult one to make. It is made more difficult by the lack of information and common misperceptions often held by individuals and even healthcare providers themselves about hospice care.

One nurse, who was referred to Delaware Hospice for a job opening, knew nothing about hospice care until she joined the organization. She later remarked, "I realized I was being more helpful to my patients and their families as a hospice nurse than I had been in any other nursing role. As a hospice nurse, you're able to do what you always thought you would do as a nurse—providing care and comfort."

The daughter of a patient expressed her appreciation to the staff at Delaware Hospice and said, "Your constant commitment, and outstanding care in made sure that he was never in pain, that he could breathe correctly, and made sure that he was comfortable. Also, thank you for the support that you also gave to my mother, brother, and me during this difficult time."

Another family wrote of their gratitude for their father's hospice care: "When we first started this adventure, we had no idea what to expect. Cancer was unfamiliar to us. We had no knowledge of how to care for a terminally ill person. We just wanted to honor my dad's wish not to pursue aggressive treatment for his cancer and we wanted the end of his life to come gently, filled with love and compassion, in the comfort of home. And with your support and compassion, we know that wish was fulfilled."

A major component of hospice is the fact that it encompasses the entire family. Through an interdisciplinary approach, hospice addresses not only the patient's physical needs, but also the emotional, spiritual and practical needs of those involved with the patient.

When a patient is admitted to Delaware Hospice, a team of professionals begin one-on-one visits to the patient and family to assess their needs and to create a care plan that will best meet those needs. A hospice team includes a nurse, certified nursing assistant, social worker, and chaplain.

Ultimately, the quality of life experienced by patients and families in hospice programs far exceeds that of those who didn't. That, in and of itself, would make hospice a preferred choice for end of life. In the economic terms of reducing healthcare costs, hospice care would also be the choice.

During an interview on CNBC with Erin Burnett, John Keyserling, Vice President of Public Policy, Alliance for Care at the End of Life, said that research has shown an inverse relationship at end of life between the amount of money spent and patient and family's satisfaction with services. You spend less in a hospice setting as opposed to acute interventions in acute care settings, and patients and families are more pleased with services and the end of life experience (<http://www.cnbc.com/id/15840232?video=1200483943&play=1>).

Several formal studies have concluded that hospice care decreases health care costs. For example, a Duke University Study reported that costs were reduced for non-cancer patients through 154 days of care and for cancer patients through 233 days of care.

The impact that better utilization of hospice services can have on health care costs becomes even more dramatic when you examine Medicare statistics.

In 2007, 38.8% of deaths in the U.S. were under hospice care, and the average length of days in hospice was 67.4 days. The National Hospice and Palliative Care Organization (NHPCO) estimates that for every hospice patient, two more could benefit from hospice.

Looking at Medicare costs overall, 27% of Medicare costs occur in the final year of life. Last year, Medicare's budget was \$477 billion; for patients in their last year of life, \$143 billion; and for the last month of life, \$47 billion.

NHPCO reports that 98% of families served by hospice are willing to recommend its care and services to others. Clearly, families who have chosen hospice for their end-of-life care feel that they made the right choice. That choice has not only brought a better quality of life at a critical time, but a reduced healthcare cost as well.

All organizations supported through Medicare will most likely be confronted with the possibility of cuts to their reimbursements.

However, there exists great potential to reduce health care costs in the U.S. by increasing the number of individuals who choose hospice care when they face the end of life. Any future healthcare reform legislation would serve the public well to include provisions for protecting hospice care as well as encouraging the exchange of information between patients and their physicians regarding end of life care.



DNA

Reporter

The Official Publication of the Delaware Nurses Association

Online Supplement Edition of the Reporter

Data Bits



Dot Baker, RN, MS(N), CNS-BC, EdD
Professor, College of Health Professions –
Nursing, Wilmington University



Dot Baker

A first Google search reveals a web page with 15 definitions of “palliative care.” Key words are: relieve suffering, improve quality of life, advanced illness, serious life-threatening condition, pain and symptom control, unlikely to cure, client, family, interdisciplinary team approach, all stages of treatment, comprehensive approach, holistic

dimensions, individual (needs, values, decisions), ease transitions between care settings, etc. The Center to Advance Palliative Care (CAPC) offers a chart that differentiates among palliative care, hospice care, case management, pain management, and geriatrics @ <http://www.capc.org/building-a-hospital-based-palliative-care-program/case-definingpc/designing/presenting-plan/pc-vs-other/>

This column presents a variety of professional organizations and resources about palliative care and hospice care. Most of the websites can serve healthcare professionals and consumers. Of interest, the Center to Advance Palliative Care offers an informative link to state-by-state reports cards about palliative care.

PROFESSIONAL ORGANIZATIONS & RESOURCES	INTERNET ADDRESS
<p>Center to Advance Palliative Care (CAPC) >Offers tools, training, & technical assistance >Includes building a hospital-based palliative care program and palliative/hospice care across hospitals and long term care >Offers research resources >Publishes <i>Journal of Palliative Care</i> >Offers e-learning >Has a link to state-by-state report card on access to palliative care with state, regional, & national rankings & provider directory resource</p>	<p>http://www.capc.org/</p> <p>http://www.capc.org/reportcard/</p>
<p>National Hospice & Palliative Care Organization (NHPCO) >Offers palliative care practice guidelines, legal & regulatory resources that include a sample palliative care agreement, and articles of interest >Publishes <i>Journal of Pain and Symptom Management</i>, newsletters, and others >Offers end-of-life care resources</p>	<p>http://www.nhpco.org/i4a/pages/index.cfm?pageid=4646&openpage=4646</p> <p>http://www.nhpco.org/i4a/links/?pageid=3287&showTitle=1</p>
<p>Hospice and Palliative Nurses Association (HPNA)</p>	<p>http://www.hpna.org/</p>
<p>International Association for Hospice & Palliative Care (IAHPC) >Offers global perspective and multiple publications, including <i>Palliative care in the developing world:Principles and practice</i></p>	<p>http://www.hospicecare.com/</p>
<p>National Palliative Care Research Center (NPCRC) >Promotes & facilitates palliative care research, features current news, resources, & grant information. This NPCRC website describes 2009 research that examined the influence of palliative care interventions on quality of life and mood for patients with advanced cancer. The research was conducted by Marie Bakitas, a doctorally-prepared advanced practice nurse.</p>	<p>http://www.npcrc.org/</p>
<p>End-of- Life Nursing Education Consortium (ELNEC)</p>	<p>www.aacn.nche.edu/ELNEC</p>
<p>Palliative Care Resource Center (Medscape)</p>	<p>http://www.medscape.com/resource/hospice</p>
<p>Palliative Care: Research and Treatment – peer-reviewed electronic journal with clinical, scientific, and policy issues</p>	<p>http://www.la-press.com/palliative-care-research-and-treatment-journal-j86</p>
<p>Search “palliative care” or “hospice care” at these sites</p>	
<p>National Cancer Institute (NCI)</p>	<p>http://www.cancer.gov/</p>
<p>National Institutes of Health (NIH)</p>	<p>http://www.nih.gov/</p>
<p>Agency for Healthcare Research & Quality (AHRQ)</p>	<p>http://www.ahrq.gov/</p>
<p>Robert Wood Johnson Foundation (RWJF) >Offers publications and research about end-of-life and palliative care @ http://rwjf.org/pr/topic.jsp?topicid=1194 The website offers tools, journal articles, and issue & policy briefs. RWJF offers information about A National Framework and Preferred Practices for Palliative and Hospice Care @ http://rwjf.org/pr/product.jsp?id=18736</p>	<p>http://rwjf.org/</p>

American Nurses Association (ANA)	http://www.nursingworld.org/default.aspx
Sigma Theta Tau International Honor Society of Nursing	http://www.nursingsociety.org/default.aspx
Centers for Disease Control and Prevention (CDC)	http://www.cdc.gov/
World Health Organization (WHO)	http://www.who.int/en/
National Center for Complementary and Alternative Medicine (NCCAM)	http://nccam.nih.gov/
Mayo Foundation for Medical Education & Research	http://www.mayoclinic.com/
Beth Israel Dept. of Pain Medicine & Palliative Care	http://www.stoppain.org/palliative_care/ethics.html
British Medical Society (palliative care ethics and position papers)	http://palliative.info/pages/Position.htm
Medline Plus	http://www.nlm.nih.gov/medlineplus/medlineplus.html
Joint Commission EVIDENCE-BASED PRACTICE	http://www.jointcommission.org/

Cochrane Collaboration indicates about 78 responses for "palliative nursing." This number does not reflect the numerous subtopic areas. Recent topics include: palliative care for older persons in nursing homes, pain & palliative/supportive care, non-invasive interventions to improve quality of life and well-being patients with lung cancer, airway conditions, prostatic conditions, wounds, neonatal, etc. This page lists information about Cochrane Review Groups & selected reviews in areas such as: acute respiratory infections; bone, muscle, & joint; breast cancer, colorectal cancer, peripheral vascular; and pain, palliative care, and supportive care @ <http://www.cochrane.org/consumers/reviewgrp.htm>

Examples of NURSING RESEARCH ABOUT PALLIATIVE CARE

>**American Cancer Society and National Palliative Care Research Center** (2009) announced "Palliative Care Research To Benefit From \$1.5 Million Award" for research grants to researchers at eleven institutions for studies aimed at reducing suffering for seriously ill patients and their family caregivers. The studies will be conducted over the next two years.

>**National Institute of Nursing Research** awarded \$1.4 M to the University of Rochester School of Nursing to conduct a 4-year study about palliative care in hospitals.

>**Hospice & Palliative Care Nurses Association** (2009) recognized Dr. Denice Sheehan and Dr. Deborah Witt Sherman for their extensive contributions toward the palliative care philosophy and research.

>**Medscape** offers palliative care topics in the "Monthly Reports of Nursing Research" from the National Institute of Nursing (NINR) @ http://www.medscape.com/index/section_1221_0

>**National Institute of Nursing Research** (2009) discusses research findings about improving palliative care and communication in the ICU (American Nurse Today) @ <http://www.americannursetoday.com/article.aspx?id=4514&fid=4476>

Examples of BOOKS & PUBLICATIONS

>**American Nurses Association.** (2007). *Hospice and palliative nursing: Scope and standards of practice*. Silver Spring, MD: Nursesbooks.org and Hospice and Palliative Nurses Association.

>**Ferrell, B., & Coyle, N.** (2006). *Textbook of palliative nursing* (2nd ed.). New York: Oxford University Press.

>**Fins, J.J.** (2006). *A palliative ethic of care: Clinical wisdom at life's end*. Sudbury, MA: Jones & Bartlett.

>**Kuebler, K.K., Davis, M.P., & Moore, C.D.** (Eds.). (2005). *Palliative practices: An interdisciplinary approach*. St. Louis, MO: Elsevier Mosby.

>**Lentz, J.** (2009) Hospice and palliative care: Closing the knowledge gap. *American Nurse*, 4(4), 12-14.

>**Matzo, M.L., & Sherman, D.W.** (2006). *Palliative care nursing: Quality care to the end of life* (2nd ed.). New York: Springer.

>**Mitchell, G.** (Ed.). (2008). *Palliative care: A patient-centered approach*. Abingdon, UK: Radcliffe Publishing Ltd.

>**Old, J.L., & Swagerty, D.L.** (2008). *A practical guide to palliative care*. Philadelphia: Lippincott Williams & Wilkins.