

Hospital-Based Palliative Care Units: Answering a Growing Need

Anthony N. Galanos, MA, MD

The central question confronting healthcare professionals and institutions with regard to end-of-life and palliative care is: How do we relieve the suffering that patients and families experience as they struggle to know what to do with serious and possibly terminal illness when it occurs? How do they navigate a medical system that offers few options if cure is not possible, cannot prognosticate with any certainty, and does not allow for the natural ebb and flow of uncertainty in medical decision making? It would seem that “palliative care,” with its attention to caring, as well as curing, and its comfort with aggressive, as well as hospice care, is the philosophy of care that can best assist patients and families as they traverse the continuum from diagnosis through symptoms and treatment to an eventual outcome that may include hospice and bereavement.

There are two ways to look at palliative care: it can be seen as the natural extension of where aggressive, cure-oriented conventional therapy ended, i.e., what do you do for people for whom no evidence-based cure or therapy is available? Or, secondly, palliative care can be conceptualized as hospice, but much further upstream. Indeed, hospice and palliative care are not mutually exclusive. Hospice is ultimate palliative care, but is defined by a time limit and regulations surrounding a Medicare benefit. Palliative care, by contrast, can begin at the time of diagnosis, or any point thereafter, when patients and families may have already begun to suffer secondary to physical symptoms, anxiety and uncertainty, and have needs outside of the traditional biomedical model of care. The clinical events that lead people into the hospital have no predetermined outcome, and there the sorting out process must begin.

As an illustration, Morrison and Meier¹ describe the case of an 85-year-old man with class IV heart failure, hypertension, and moderate Alzheimer’s disease who is admitted to the hospital after a hip fracture. This is his fourth hospitalization in the past year and his 84-year-old wife feels overwhelmed by his medical and personal care needs. The question becomes what might his doctor do to address his needs, alleviate his suffering, and facilitate discharge from the hospital and subsequent care

at home? While this patient may eventually choose hospice, it is his current dilemma, blossoming in the hospital, which creates the need for palliative care services.

Indeed, when problems with end-of-life care are described, reference is often made to situations that occur in the acute care hospital setting. Concomitantly, while place of death is shifting more and more away from the hospital, it still remains the most likely site of death for North Carolinians and for Americans in general. It is important to ask why the hospital is seen in such a negative light when one has a terminal illness and why there is a need for concentrated palliative care efforts in these facilities. Aren’t hospitals the very places where high-quality care at the end of life would be expected?

Why the Focus on the Hospital in Discussions of Palliative Care?

Noting that as many as 50% of patients currently die in acute care hospitals, the Acute Care Hospital Working Group, one of eight working groups convened as the National Consensus Conference on Medical Education for Care Near the End of Life, delineated a host of barriers to good end-of-life care in the acute care hospital:

- Shorter lengths of stay; hence, health professionals being trained in these settings do not see the trajectory of end-stage illnesses and fail to appreciate the needs of dying patients.
- Multitude of specialist physicians, with no one seemingly responsible for the integration of care needs in a patient-centered way.
- Emphasis on the “great case” with an accent on the disease and technical procedures at the expense of the bigger picture of the impact of the illness on the patient and family.
- Subtle messages such as death as a medical failure and that physicians should not express personal emotions, and other negative attitudes about dying.

Anthony N. Galanos, MA, MD, is Associate Professor of Medicine and Director of Clinical Palliative Care Service at Duke University Medical Center. He is also an Associate Faculty Member of the Duke Institute on Care at the End of Life and a Faculty Scholar with the Open Society Institute’s Project on Death in America. He can be reached at galan001@mc.duke.edu or Box 3003 Duke University Medical Center, Durham NC 27710. Telephone: 919-660-7552.

- Lack of essential communication and symptom-control skills among supervising physicians.
- Few end-of-life educational resources available for health professionals.²

Why Should Hospitals Respond? And in What Ways?

Hospitals should respond because the people they serve and the people who work in them want a better response to incurable disease. Data from public opinion polls and the lay press are unequivocal. The majority of Americans (74%) expect their physicians to be confident and competent in providing them with care when they do develop a life-threatening illness.⁴ The public expects that the problem of suffering has been addressed directly in medical education⁵ and is not uniformly in favor of aggressive care at the expense of comfort and functional status. For example, an American Association of Retired Persons (AARP) *Modern Maturity* survey of people's attitudes about death and dying, based on 1,800 interviews of Americans 45 years of age and older found that the older you are, the less afraid you are of dying and being in pain at the end of life. In the overall sample, 71% of people believe there is a point at which costly health treatments should be stopped and the numbers were even higher among people in higher income brackets, with 77% of those who earn \$50,000 or more a year agreeing that at some point aggressive treatments may do more harm than good.⁶

Closer to home, the AARP North Carolina End-of-Life Care Survey⁷ sampled AARP members age 50 and older and had a response rate of 45%. Of the end-of-life concerns, almost 90% say that total physical dependency would be worse than death, and 70% say that not being able to communicate their wishes or that living with great pain is worse than death. More than 90% had heard of hospice, though only a quarter were aware that Medicare pays for it. Among those who know about hospice, three-quarters reported they would want hospice support if they were dying.

In addition, the national Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*,⁸ and policy statements from various clinical organizations, such as the American Board of Internal Medicine and the American Geriatrics Society^{9,10} have advanced the argument that the pub-

lic is better informed with regard to issues pertaining to end-of-life and palliative care through community organizations such as Project Compassion in Chapel Hill, North Carolina¹¹ or through media such as *Time* magazine,¹² the *Wall Street Journal*,¹³ ABC's *NIGHTLINE* with Ted Koppel,¹⁴ and National Public Radio.¹⁵ One outcome of such public discussion of death, dying, and the relief of suffering is that hospitals are now being judged by their ability to provide palliative and or hospice services.^{16,17,18} Ultimately, hospitals must listen to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), which has issued a set of standards/guidelines regarding care at the end of life:

"The patient at or near the end of his or her life has the right to physical and psychological comfort. The hospital provides care that optimizes the dying patient's comfort and dignity and address-

*es the patient's and his or her family's psychosocial and spiritual needs... and staff is educated about the unique needs of dying patients, their families and caregivers."*¹⁹

This last comment regarding "staff" is significant. Caregivers in the hospital need support and guidance as they care for patients for whom there is no cure. Nurses and physicians have voiced concerns over the lack of patient involvement in treatment decisions and the overuse of

mechanical ventilation, dialysis, and resuscitation.²⁰ Our own research at a tertiary care teaching center has shown that among attending physicians, house officers, nurses, and family members, no two of these four groups saw the last week of life in the hospital in the same way, and levels of satisfaction differed among the four groups.²¹ It behooves hospitals to provide better advice and support to those front-line professionals responsible for caring for the terminally ill. A palliative care team can provide the support needed for end-of-life care and aggressiveness of care.

How Should the Hospital Respond? Is the Hospital-based Palliative Care Team Part of the Answer?

In response to the 1998 American Hospital Association Survey, 30% of hospitals that responded to the survey reported having a hospital-based palliative care program with another 20% planning to establish one.²³ Palliative care programs have been based primarily in medical oncology or general medicine

"Palliative care is not a way out, but a way through, and it allows patients to have hope and an opportunity to live as fully and functionally as they can for as long as they can. Hospitals are a place of miracles and cures, but when that can not be the outcome, we '...palliate often, and comfort always.'"

divisions and a consultation service was the most common clinical entity. Another report based on the same data concluded that, given the need, palliative care services were slow to be institutionalized in the hospital setting.²⁴ As Hanson concludes elsewhere in this issue of the *North Carolina Medical Journal*,³⁰ there are multiple models of palliative care services affiliated with hospitals and the process is “not yet standardized,” but outcome data are now starting to build.^{25,26}

The Essentials of Palliative Care

Palliative care, by definition, is an interdisciplinary team event. Depending on available resources, most palliative care teams have a nurse practitioner as the hub of the team to assure continuity of care. The nurse practitioner is backed up by an attending physician and, in some centers, a geriatric medicine or oncology fellow. It should be noted that there are roughly 43 active or emerging United States fellowships in palliative medicine and Duke University Medical Center will offer a program as of July 1, 2005.²⁵ Critical members of a palliative care team include a chaplain, a social worker, and rehabilitation specialists if increased function is needed for quality of life. In some cases, a psychiatrist may be needed to address issues such as depression and delirium if the team is not comfortable with the complexity of these issues at the end of life. It is not the composition of a palliative care team that is important, but rather that personnel with appropriate skills are available to meet the needs of a particular patient at a particular time in his/her continuum of care. The most important player on the team will vary by the patient and by patient need. “No man can be rendered pain free whilst he still wrestles with his faith. No man can come to terms with his God when every waking moment is taken up with pain or vomiting.”²⁸

Some potential roles of the clinical palliative care team include offering advice and support to the patient’s caregiving team on symptom control and psychosocial and existential issues. This kind of support is clearly needed for the patient’s family as well. Another role is educating hospital staff (pursuant to the JCAHO standard) and serving as a liaison between the hospital, hospice, or other facets of the continuum of care. This role would suggest that the palliative care team is present to reduce symptoms and suffering, to meet family and patient preferences, and to help negotiate goals of care. Meeting these needs should lead to improved patient and family satisfaction, as well as that of the hospital staff, while improving utilization

of hospital resources, e.g., length of stay, number of intensive care unit (ICU) days, readmission rate, unnecessary emergency room use, and the timing and appropriateness of hospice referrals.

Institutions that have a designated geographic area and a defined palliative care unit have demonstrated incredible outcomes.²⁶ Having the designated area allows for total management of the patient, and for an atmosphere of enlightened patient-centered care. A step down from this level of care that still allows primary care of the patient, but does not entail a separate palliative care unit, is the “scatter-bed” model. In hospitals where beds may be at a premium, the “scatter-bed” model allows the palliative care team to take over the patient’s primary care in the same bed that he or she was residing in at the time of initial consultation. In other words, when the palliative care consult team visits a patient in the hospital and finds that the needs of the patient can be better met by the palliative care team, then the patient will stay in that unit bed, but the primary care will be provided by the palliative care team. While it has its disadvantages, one clear advantage of the “scatter-bed” model is that multiple units in the hospital are exposed to and learn the fundamental principles of palliative care. In some arenas, primary care of patients may not be an option, so a “consult-only” service is the best mode of operation.

Whatever model of care is feasible at a particular institution, it is important not to approach the staff with an attitude of “we are here to show you how to do it, because you have been doing it poorly,” but rather to provide added value to what is in place. Our experience has shown us that once nurses, chaplains, and physicians working on the unit understand the palliative care clinical team’s role and purpose, they welcome our intervention and often participate with us in family meetings and discussions of care goals. While these activities clearly lead to better patient, family, and staff satisfaction, we are collecting data on cost savings to the institution. As in the example of the palliative care unit at Medical College of Virginia,²⁶ to collect data on patients that are matched on diagnosis and other variables, and then to compare cost and other data for those with and without palliative care intervention, can be a powerful argument to hospital administration and to those who may not be familiar with this type of care.

In essence what we have been talking about is that an either/or (cure or not) approach to medicine does not work for patients, families, and hospital staff. We can expand the options and choices of the people we serve by employing palliative care in the hospital. That way, we relieve suffering and change the

Sources Relevant to Initiating a Hospital-based Palliative Care Unit/Program

The Hospital and Healthsystem Association of Pennsylvania has expanded its Hospital-Based Palliative Care Consortium to serve hospitals nationwide and can be accessed via its website at <http://www.hbpc.org>. The Center to Advance Palliative Care, a national initiative supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine, has produced an outstanding monograph: “The Case for Hospital-Based Palliative Care,” that outlines the rationale for starting such a program with an emphasis on data that would appeal to hospital administrators.²² Readers are directed to the Center to Advance Palliative Care (CAPC) website where voluminous amounts of information are available, eg, “Palliative Care in Hospitals: Making the Case,” www.capcmssm.org.

focus from the hospital, to the patient and those close to him or her. It is the patient and family who have come to the hospital for answers to their conundrum. In response, the hospital-based palliative care team does not emphasize what will be taken away, but what will be done *for* the patient and family despite a life threatening illness. Palliative care is not a way *out*,

but a way *through*, and it allows patients to have hope and an opportunity to live as fully and functionally as they can for as long as they can. Hospitals are a place of miracles and cures, but when that can not be the outcome, we "...palliate often, and comfort always."²⁹ **NCMJ**

REFERENCES

- 1 Morrison RS and Meier DE. Palliative Care. *N Engl J Med*. 2004; 350: 2582-2590.
- 2 Weissman DE, Block SD, Blank L, et al. "Recommendations for Incorporating Palliative Care Education into the Acute Care Hospital Setting." Acute Care Hospital Working Group. *Acad. Med.* 1999; 74: 871-877.
- 3 Danis M, Federman D, Fins JJ et al. Incorporating Palliative Care into Critical Care Education: Principles, Challenges and Opportunities. *Crit Care Med*. 1999; 27: 2005-2013.
- 4 American Medical Association: Public Opinion on Health Care Issues, 1997. Chicago, IL, American Medical Association, August 1997.
- 5 Cassel EJ. The Nature of Suffering and the Goals of Medicine. *N Engl J Med*. 1982; 306: 639-645.
- 6 Redford GD. "Their Final Answers: An Exclusive *Modern Maturity* Survey" *Modern Maturity*. September-October 2000: 67-68.
- 7 Straw G and Cummins R. AARP North Carolina End of Life Care Survey. July, 2003. pgs. 1-3. <http://research.aarp.org>.
- 8 Approaching Death: Improving Care at the End of Life. Committee on Care at the End of Life. MJ Field and CK Cassel, Editors. Institute of Medicine. National Academy Press. Washington, DC 1997.
- 9 Rudberg MA, Teno JM, Lynn J on behalf of the Ethics Committee of the American Geriatrics Society. Developing and Implementing Measures of Quality of Care at the End of Life. *J Am Geriatr Soc*. 1997; 45: 528-530.
- 10 "Caring for the Dying: Identification and Promotion of Physician Competency." Project of the American Board of Internal Medicine. Christine K. Cassel, Project Chair. American Board of Internal Medicine. 1996 - <http://www.abim.org>.
- 11 Project Compassion. PROJECT COMPASSION is a community-based organization providing education, advocacy, and support for all people as they deal with serious illness, death and grief as a natural part of life. 180 Providence Road, Suite 1-C, Chapel Hill, NC 27514. www.project-compassion.org.
- 12 *TIME*, "Dying on Our Own Terms" September 18, 2000 Cover
- 13 Naik G. "Unlikely Way to Cut Hospital Costs: Comfort the Dying." *The Wall Street Journal*. March 10, 2004. WSJ.com
- 14 *Nightline*. "A Good Death". December 10, 2003.
- 15 "The Last Days of Kitty Shenay" An in-depth account by reported John Biewen explores the birth of the hospice movement and traces its influence in the final months of a North Carolina woman: "The Last Days of Kitty Shenay" (<http://americanradioworks.publicradio.org/features/hospice/index.html>).
- 16 *US News and World Report*. "America's Best Hospitals 2004. Cover story, July 12, 2004.
- 17 Colias, M. "How Hospitals Measure UP. *Modern Healthcare*, The Solucient 100 Top Hospitals. May 24, 2004 pgs. 26-29.
- 18 *British Medical Journal*. 2004; 328: 607. (bmj.bmjournals.com/cgi/content/full/bmj;328/7440/607).
- 19 Joint Commission for the Accreditation of Healthcare Organizations. Standard on Palliative Care. PC.8.70
- 20 Solomon et al. Decisions Near the End of Life: Professional Views of Life-sustaining Treatments. *Am J Public Health*. 1993; 83: 14-23.
- 21 Poppe AM, Pieper CF, Steinhauer KE., Galanos AN Satisfaction with End of Life Care: Provider and Family Perspectives. manuscript in preparation; data presented at the Annual Meeting of the American Geriatrics Society, Baltimore Maryland, 2003.
- 22 The Case for Hospital-Based Palliative Care: Why Leading Hospitals are Starting Palliative Care Programs. Meier ED. Director, Center to Advance Palliative Care. October 2002. www.capc.org.
- 23 Weismann, DE. The Growth of Hospital—Based Palliative Care. *J of Pall Med*. 2001; 4: 307-308.
- 24 White KR, Cochran CE, and Patel UB. Hospital Provision of End of Life Services: Who, What and Where. *Med Care*. 2002; 0: 17-25.
- 25 Elsayem A, Swint K, Fisch MJ, Plamer JL, Reddy S, Walker P, Zhukovsky D, Knight P and Bruera E. Palliative Care Inpatient Service in a Comprehensive Cancer Center: Clinical and Financial Outcomes. *J Clin Oncol*. 2004; 22: 2008-2014.
- 26 Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, and Hager MA. A High-Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End of Life Care Costs. *J of Pall Med*. 2003; 6: 699-705.
- 27 Von Gunten CF and Lupu D. for the American Board of Hospice and Palliative Medicine. Development of a Medical Subspecialty in Palliative Medicine. *J Pall Med*. 2004; 7: 209-219.
- 28 Oxford Textbook of Palliative Medicine. Second Edition. EDs. Doyle D, Hanks GWC, and MacDonald N. Oxford University Press. Introduction. 1998. pg 6.
- 29 *Anonymous, 16th Century*, quoted by Holman GH. *Hospice/Palliative Medicine: Principles and Practice*. Federal Practitioner. January, 1999, pg 33.
- 30 Hanson, LC. Palliative Care: Innovation in Care at the End of Life. *North Carolina Medical Journal* 2004;65(4): 202-208.