A Good Death: Changing the Script for End-of-Life Care

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Having been engaged in the delivery of end-of-life care for more than 25 years, I am equally baffled and elated at this juncture. I am baffled by knowing just how long it has taken for medicine to recognize the value of palliative care, and I am elated that in many hospital circles there seems to be a newfound infatuation with, and respect for, the practice.

Since hospice care began, in part, as a mini-revolt against traditional treatment of the dying and the medical establishment, it’s perhaps not surprising that hospitals and physician specialists were not initially interested in becoming familiar with its tenets of care. There was little incentive to minimize procedural interventions, even in the face of incurable illness. Death was, and for the most part still is, viewed as professional failure; physicians were not prepared in medical schools to consider the concept of a “good death.”

The Historical Perspective
Hospice was developed as a patient-centered movement, primarily driven by nursing, pastoral care, and social work—a softer approach from less data-driven disciplines. Medicine was fulfilling its sanctioned role of pushing the boundaries of treatment specifically aimed at holding back the enemy—death—at all costs. Simultaneously, we began to believe the myth that death could be prevented, or at least prolonged indefinitely. We had nearly conquered death with the latest treatments and medical discoveries; TV shows inaccurately portrayed and glamorized CPR success rates.

Three decades following its humble beginning, hospice care in America has become the gold standard of end-of-life care. Founded largely by mission-driven and philosophically grounded advocates, programs began in basements of churches and in public health departments. The demographics today indicate a large and diverse group of hospice and palliative care providers, including board certified hospice and palliative medicine physicians. The National Hospice and Palliative Care Organization estimated that in 2009 there were 3,600
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Hospice agencies with a total of 5,000 site locations. Nearly 58 percent of the hospice agencies were freestanding or independent hospices. Among the others, only about 20 percent operated as a part of a home health agency and another 20 percent were part of a hospital system (NHPCO 2010). Hospice programs have developed primarily as community-based initiatives. As such, they have a clear and compelling focus—enhancing the quality of care for those approaching life’s end. Many seek to extend palliative care expertise across the continuum of healthcare and are poised to partner with assisted-living, long-term care, and hospital facilities.

The Interface of Palliative and Hospice Care
Hospice care is typically provided at home or in a homelike setting, while palliative care is more commonly provided as a specialty consult service within a hospital or other institutional setting. Although in many countries, the terms hospice and palliative are used interchangeably, the payment mechanism in the United States (primarily Medicare) is responsible for a line of demarcation, albeit somewhat arbitrary, between palliative and hospice care. Hospice care in America is reserved for those with a defined prognosis, despite the fact that prognostication is not a science and physicians often overestimate a patient’s anticipated survival (Murphy et al. 2000). In order to access hospice care through Medicare and most insurance plans, a physician is required to provide a prognosis certification of six months or less life expectancy if the disease runs its anticipated course. Without regulatory barriers to prohibit the simultaneous provision of cure-oriented or disease-modifying therapy with comfort-oriented palliative care, the latter may be easier to introduce to patients and families. Dr. Joanne Lynn, one of the researchers who conducted the SUPPORT project (1995), has referred to the phenomenon as the “dance of silence”: simply following a cultural script and planning the next treatment or procedure, without engaging in meaningful conversation about what patients want. Palliative medicine specialists are changing those cultural scripts. The Medicare requirement for certification of a less-than-six-month prognosis and the difficulty in making the decision to forego cure-oriented therapy continue to be cited as reasons for delayed hospice referrals. In 2009, nearly half of hospice patients died or were discharged within 14 days of admission (NHPCO 2010). Knowing how and when to delicately balance the hope for curing with the desire for comfort, in a holistic sense, takes a great deal of skill. Involving a team of palliative care professionals earlier in a person’s disease process and/or during hospitalization positions them to help patients make smooth transitions, whether to home or to a nonhospital setting, for end-of-life care. When this is not feasible, the palliative care team can help ensure comfort and dignity for deaths that occur within the hospital setting.

The Academic Medical Center Model
Over the past decade, the discipline of palliative medicine has been honed and legitimized, first entering academic hospitals, then, more recently, community-based hospitals. In institutions that serve as academic teaching hospitals, there is
great opportunity to explore best practices for end-of-life care from both theoretical and practical perspectives. Medical practitioners in training are eager to learn and have the opportunity to interact with a variety of professionals and disciplines. Institutions that have incorporated bioethics, palliative medicine, and patient-centered care into the curriculum are getting it right.

Fromme, Guthrie, and Grueber have provided a clear and compelling example of just how far some institutions have come in recognizing the essential value of palliative care. At OHSU, palliative care appears to be delivered with intention and is beginning to permeate the medical culture as optimal “treatment” for the chronically and critically ill, defined as those “for whom the burdens of hospital or disease-oriented care are beginning to outweigh the benefits.” Clearly a pioneer in quality palliative care, OHSU has taken one step further with the creation of the Palliative Medicine and Comfort Care Team (PMCCT), whose philosophy is to “create a palliative healthcare community within the hospital to ensure that, wherever they go, patients will have access to palliative care services.” Most hospital-based palliative care programs are less comprehensive than the PMCCT at OHSU. Having such a defined level of commitment, expertise, and approach added to existing care is extremely valuable; over time incorporation of palliative care becomes the standard of care. However, as with any hospital-based team, the focus revolves around hospitalized patients including OHSU. As Fromme and colleagues state, “the PMCCT seeks to improve quality of life for hospitalized patients across a broad range of diagnoses and prognoses.” In addition to providing improved episodes of care within hospital settings, we must also ensure that post-acute transitions are effectively managed and sustained.

**Community-Focused Health Systems and Hospice–Palliative Care Partnerships**

Hospitals and health systems that are less teaching-focused than OHSU can also offer effective palliative care services. Organizations that partner with well-integrated post-acute palliative and hospice programs are in a unique position to offer exceptional services, and perhaps more efficiently than academic medical centers. My observations and experience demonstrate that effective partnerships between health systems and community hospice providers can be highly successful and offer unique advantages. Fromme and colleagues acknowledge that hospice programs often have the most palliative expertise. The challenges, as they describe them, are supporting hospice personnel who bring their expertise into the hospital and securing seamless transitions across settings and goals of care.

Approximately 60 percent of hospice agencies report having operational palliative consultation services (NHPCO 2010). Effective post-acute transitions occur when hospice/palliative care providers and hospitals work well together. In reality, not all hospice and palliative care providers are the same. I encourage discharge planners to get to know the quality, expertise, and capacity of their local hospice providers and advocate for meaningful engagement to help ensure the optimal experience for patients and their families.

Hospice and Palliative Care of Greensboro (HPCG), North Carolina, a community-based not-for-profit organization, has maintained a formal joint
venture partnership with Moses Cone Health System for more than 25 years. Although each is an independent entity, the organizations have drawn on their collective expertise to advance quality care across settings, consistent with patient and family wishes. The health system offers palliative care in its hospitals and a palliative consultation service for its hospitalized patients, using a shared staffing model (with HPCG) to ease transition to home, inpatient hospice, or other appropriate services. Griffith and White (2003) identify Moses Cone as an example of a progressive organization. I believe that the joint venture between this health system and its local hospice partner is but one example of how making decisions and implementing strategies in support of a common vision and shared values clearly produce excellence. As the imperative to develop an effective care continuum strengthens along with pressures to improve quality and reduce costs, this community-focused health system is well positioned to do so. The joint venture was innovative when it began in 1984 and successfully remains so today.

The much larger San Diego Hospice/ The Institute for Palliative Medicine has maintained effective informal partnerships with multiple area hospitals and health systems. One of those relationships is with Scripps Health. Recently I had the opportunity to discuss the history of the relationship with Dr. Bill Stanton, chair of the Network Cancer Program for Scripps Health and the Medical Director of Scripps Cancer Center; and Kathleen Pacurar, president and CEO of San Diego Hospice. An early San Diego Hospice board mem-

ber, Dr. Stanton is still actively engaged with San Diego Hospice & the Institute for Palliative Medicine. I recognized him as bridge builder and, more important, a patient advocate. His continued advocacy and involvement clearly illustrate the value of having a strong hospice and palliative care champion. It is a critical element in developing a successful palliative care strategy and creating synergy between inpatient and post-acute providers. Fromme and colleagues state that the absence of a strong palliative care champion is the biggest challenge to advancing palliative care services.

My most recent professional experience is with Hospice & Palliative Care Charlotte Region (HPCCR), a large community-based provider that has served the greater Charlotte, North Carolina, region for more than 30 years. HPCCR has been engaged in community provider partnerships for decades. It started with one local hospital, helping create a small inpatient hospice unit within Presbyterian Hospital. Then, in 2003, HPCCR approached Carolinas Healthcare System (CHS) with what was then considered a radical idea: the development of a hospital-based palliative medicine consultation service, provided by palliative medicine physicians and specialty level nurse practitioners employed by HPCCR. After serving one patient in 2003, the program collaboration has grown significantly over the past seven years, providing nearly 2,300 new palliative medicine consults in 2010. These efforts have expanded to six hospitals, dozens of nursing facilities, and two outpatient clinics. From initial skepticism, a highly effective palliative medicine service is currently being integrated into the fabric of care within CHS. The conclusion that may be drawn from these three
examples is that progressive healthcare providers can collaborate successfully and create synergistic partnerships that advance the delivery of palliative care and hospice services within the communities they serve.

**Honoring Patient Wishes for End-of-Life Care**

Oregon is clearly a leader in promoting the use of advance directives, including the Physician Orders for Life-Sustaining Treatment (POLST) tool. The history of the movement, and its successful outcomes, are clearly documented in Fromme and colleagues’ feature, including findings from a study of cases where emergency medical technicians (EMTs) reported that, when present, POLST changed treatment (consistent with patient wishes) in 45 percent of cases.

Within North Carolina, the Medical Orders for Scope of Treatment (MOST) tool, a brief form that summarizes patients’ care preferences, was authorized in 2007 and is slowly gaining traction. However, some EMTs, long-term care facility personnel, and hospitals have yet to recognize these physician orders. I recently spoke with a school principal who was told by her administration that such a form would not be honored for the terminally ill child who still attends her school.

There continues to be a great deal of misunderstanding about palliative care, advance care planning, and the MOST tool for those with advanced illness. Statewide education, similar to the efforts being undertaken throughout Oregon and by OHSU faculty with the Center for Ethics in Health Care, is encouraging. In our state, many hospice providers have spearheaded local community-based coalitions to advance educational initiatives with some success. The North Carolina Medical Society, with the leadership of Melanie Phelps, has created many educational tools for statewide use (see www.ncmedsoc.org). Presentations about the history and use of advance directives, including the MOST tool, have been offered throughout the state. Through collaborative efforts, these strategies can be effectively implemented throughout the country.

Education and dialogue continue to be essential. Because of these valuable resources and those who are strong advocates for them, conversations about desires for care at the end of life are being encouraged (before a crisis blurs decision making). Such prudent conversations, provided with clear, honest, accurate information and delivered with compassion and cultural sensitivity, promote informed decision making.

**Advancing Best Practice**

Community hospitals, academic teaching institutions, and multi-site health systems should aspire to integrate palliative care within the fabric of their daily culture, as OSHU and others are doing. A consensus report (Weissman and Meier 2011), “Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting,” published by the Center to Advance Palliative Care, outlines suggested criteria for identifying palliative care needs upon hospital admission and during each hospital day. If these or similar criteria and checklists are adopted and become the standard of care for patients with serious, complex, and life-limiting illness, palliative needs may emerge as the sixth vital sign, following the assessment of pain.

Community-based and academic teaching hospital efforts can also be enhanced as their staff members work alongside...
Can we help patients and families maintain hope as treatment goals are modified?

dedicated hospice professionals as collaborators across the healthcare continuum. In addition to providing palliative care beyond the hospital setting, many hospices provide community and professional education about advance care planning, having difficult patient–family conversations, and making effective care transitions.

Through focused effort and with clear intent, physicians and care teams will no longer say “There is nothing more we can do; we need to call hospice.” Instead, the standard of care will be to offer primary palliative care assessment, specialist-level consultation, and hospice care as effective and optimal treatment for comfort and healing—even in the absence of curing.

**Conclusion: Ethics and Hope at End of Life**

Drs. Weeks and Nelson, in their feature article, provide a compelling summary of the literature, which demonstrates that higher spending and utilization of healthcare—especially at the end of life—does not produce better quality of care or patient satisfaction or improve mortality. They suggest that healthcare managers and clinicians consider the ethical principles of justice, nonmaleficence, and informed consent as a basis for providing more efficient, effective, and patient-centered healthcare. Their assumption that fully informed patients choose lower intensity of care at the end of life is affirmed by the work of Temel and colleagues (2010), who found that compared with patients receiving standard care for metastatic nonsmall-cell lung cancer, those who received early palliative care chose less aggressive care at the end of life and experienced longer survival.

When patients and their families are initially coping with a serious accident or illness, they commonly hope for, if not expect, recovery or cure; modern medicine is sometimes able to provide it. If this is not feasible, hope shifts to treatment aimed at minimizing negative impact or controlling disease progression. Advancements in medicine often result in the ability to achieve these goals. The most serious challenges are presented when the benefits of the next therapy or course of action may outweigh its benefit. Weeks and Nelson assert that “doing everything” is rarely justified in these situations and that such an approach may produce overuse and unjustified hope. Yet this approach to care, even at the end of life, is still common.

Can we help patients and families maintain hope as treatment goals are modified? For those with advanced illness, palliative medicine and hospice should be presented well before death is imminent. When feasible, the transition from palliative to hospice care should be recognized and then offered as a best practice recommendation. These options are to be presented as appropriate and effective “treatment.” Patients and their families should be fully informed about the documented benefits of palliative and hospice care. In addition, practitioners might be so bold as to share that there is hope in hospice. That hope may enable a loved one to go home from the hospital, or sleep through the night without pain, or complete the family scrapbook. Hope remains for providing care that supports the “dignified and humane sequel to living” Weeks and Nelson describe.
REFERENCES