

Palliative Care: More than Just Care from a Friendly Relative

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Overview

A well-meaning board member of a large home health and hospice organization once shared that he thought palliative care must mean, “care from a friendly relative.” While half-heartedly playing on the words “pal” and “relative,” he was not far from the truth. From a literary point of view, palliative care means care intended to “cloak” symptoms as opposed to curing disease. But most imagine it to be just comfort care only, very supportive and very hospice-like.

For more than a decade, the World Health Organization (WHO) has defined palliative care as active total care of patients not responsive to curative treatment where control of pain and other symptoms and of psychological social and spiritual problems is paramount and the goal is the best possible quality of life for patients and their families. More recently, Diane Meier, at the Center to Advance Palliative Care and others have shied away from this concept of switching from curative to palliative and embraced a concept of palliative care as interdisciplinary care that aims to relieve suffering and improve the quality of life for patients with advanced illness and their families, *offered simultaneously with all other appropriate medical treatment*.¹ From this point of view, palliative care may be present from the time of intensive care unit (ICU) admission, help manage the transition as curative therapies fail, and become the predominant mode of care as terminal illness becomes apparent.

In this issue of the Journal, Laura Hanson has done an excellent job of reviewing existing shortcomings in end-of-life care. She has also reviewed comprehensive strategies such as hospice and palliative care to address these problems and innovations to make advance directives work and other strategies to improve communication and access.²

In fact, palliative care may be one of the most rapidly developing service lines in United States hospitals. As Dr. Hanson points out, almost one in five hospitals now has a palliative care service and many more have plans to create them. More than

1,500 physicians are now certified in Hospice and Palliative Medicine.³ The specialty is in the process of becoming certified by the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME). Palliative care fellowship programs are rapidly developing to meet these growing needs. Existing palliative care and hospice programs have created a more extensive body of evidence-based literature in palliative medicine and achievable, meaningful outcomes are being realized within committed institutions.

All of this must sound very exciting and academic! But from a much more practical point of view, does your institution need palliative care? What can a palliative care service actually do for you? And if you want one, how can you develop one? Many concerned healthcare providers, hospitals, and hospices are asking these same questions. Fortunately, there are tremendous resources available through the Center to Advance Palliative Care (CAPC), a national initiative supported by the Robert Wood Johnson Foundation with direction and technical assistance provided by the Mount Sinai School of Medicine.

The Center to Advance Palliative Care⁴

Diane Meier, Director of CAPC, and staff have created a wide variety of resources to assist institutions with the entire process of developing palliative care services from needs assessment to sustaining and growing existing programs. Resources include conferences, website, monographs, and leadership centers available for site visits and ongoing mentoring. These leadership centers include a variety of settings where palliative care has developed and flourished, i.e., academic medical centers, private hospitals, healthcare systems, and home health and hospice organizations. The process begins with building a case specific to the institution including needs assessment, securing support and financial considerations. While there are formulas that are specific and data driven, it is far from a “cookbook” approach. The CAPC process goes on to help design a program specific

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to the institution, develop a business plan, implement services, measure quality and impact, and even market the program.

Critical to the success of the CAPC process is the development of a core team, which includes a medical staff leader, nursing leader, hospice representative, and an administrative champion. CAPC is quick to point out that this is an ideal opportunity for hospital/hospice collaboration.

Is this a formula for guaranteed success? Of course not, but generally expected and accepted, evidence-based outcomes include reduction in symptom burden, improved patient and family satisfaction, and reduced costs. Other highly likely outcomes, but less evidence-based, suggest care concordant with patient/family wishes, patient/family/professional consensus on the goals of care, and improved continuity of care.⁵

Local Hospital-based Palliative Care Initiatives

Forsyth County, North Carolina, demonstrates two distinctly different approaches to palliative care programs developed with local initiative, but also tutored by CAPC programs. The local area hospice, a private, independent not-for-profit hospice and home health organization enjoys a longstanding, collaborative relationship with both the academic medical center and the large tertiary care private hospital in Winston-Salem. The hospice owns and operates a 20-bed freestanding inpatient hospice facility, and has an average daily census of 260 patients at home, in nursing homes, and in the facility. Hospice employees include a full-time medical director, a second full-time physician, and a geriatric nurse practitioner.

Over the past five years, the hospice has embraced the concepts of palliative care. Central to their view of palliative care and mission, the hospice strives to improve the quality of care for patients and families facing life-limiting illness across the continuum of care, regardless of diagnosis, prognosis, or treatment.

During this same time period, both the academic medical center and the private hospital responded to needs within their institutions and began to consider the development of palliative care services. Of interest, their approaches were distinctly different if not frankly opposite. The private hospital quickly developed a palliative care unit, whereas the academic medical center conducted a detailed needs assessment and gradually developed a consult service. However, both engaged medical, nursing, and administrative leadership as well as the hospice to

collaboratively develop these diverse approaches to meeting palliative care needs within the two institutions. Each has relied on hospice expertise and, under both circumstances, representatives have attended CAPC conferences and relied heavily on CAPC developed tools.

The Acute Palliative Care Unit (APCU) at Forsyth Medical Center (FMC)

Forsyth Medical Center has been a major supporter and referrer to the Kate B. Reynolds Hospice Home in Winston-Salem. Oncologists and hospitalists at FMC became concerned by the development of a waiting list for their patients in need of inpatient hospice referral. This led to the rapid development of the Acute Palliative Care Unit (APCU) to provide quality end-of-life care for hospitalized patients and their families. Hospital staff collaborated with hospice staff in planning, development, and implementation and attended CAPC conferences together. Tools for assessment and treatment were shared, and hospice staff continues to supply clinical expertise and medical direction.

The APCU admitted over 600 patients in 2003 and has achieved superlative results in family satisfaction, while simultaneously demonstrating significant cost savings once patients are transferred to the unit. Their data reflect a cost/day saving of over \$1,800 once patients are transferred into their unit from elsewhere in the hospital. In addition, APCU is the focal point for improving end-of-life care in the hospital and provides leadership for quality initiatives surrounding pain and symptom management. In direct contrast to the academic medical center, FMC quickly developed a palliative care unit to meet the needs of patients, families, and physicians. FMC is now taking steps to formally develop a consult service to identify unmet palliative care needs for patients throughout the hospital. The APCU remains one of the major referral sources for the hospice home.

The Palliative Care Consult Service (PCCS) at Wake Forest University Baptist Medical Center (WFUBMC)

The academic medical center took a different approach to meeting palliative care needs within their institution. Not surprisingly, the approach began with a detailed needs assessment to support both the educational and clinical mission of the hospital. The

Figure 1.
Palliative Care Consults by Month at WFUBMC, July 1 - May 31, 2004 = 263 pts

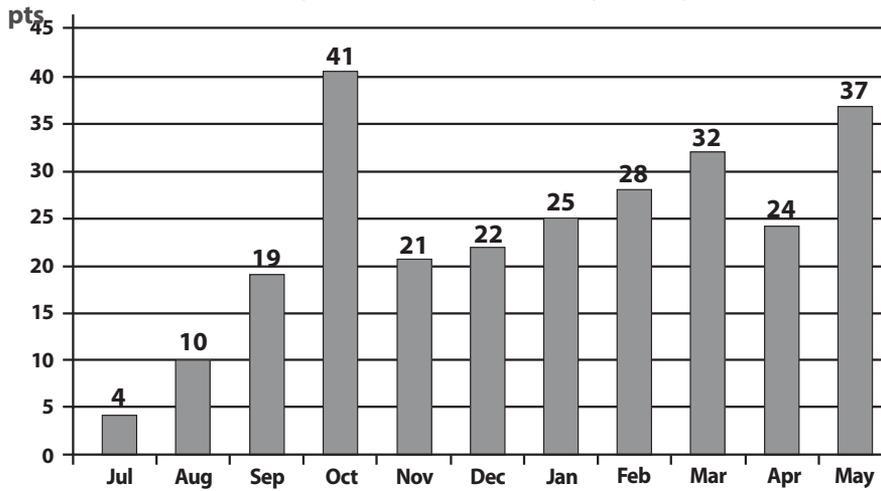


Figure 2.
Service Requesting Palliative Care Consult at WFUBMC

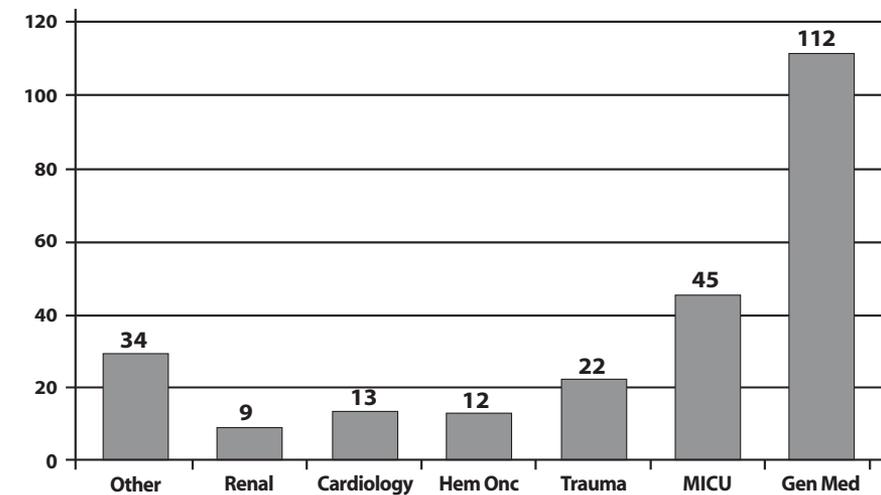
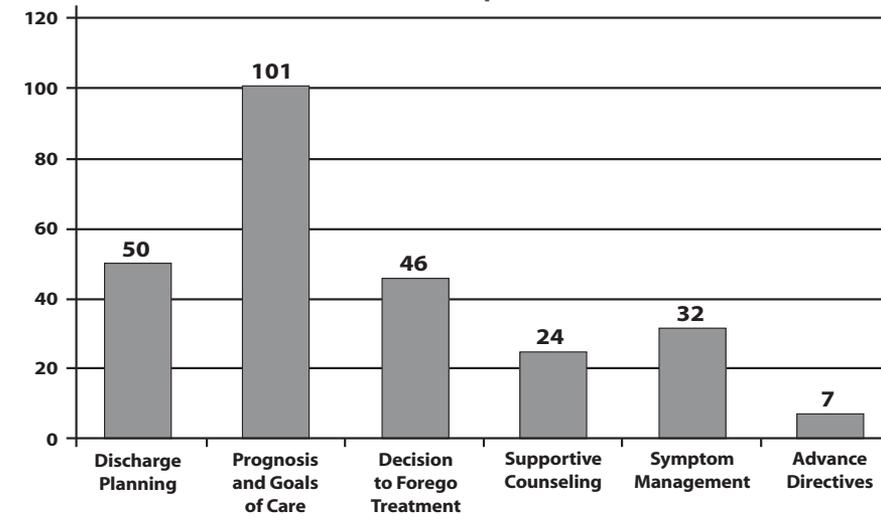


Figure 3.
Reasons Palliative Care Consults Were Requested at WFUBMC



needs assessment relied heavily on tools developed by CAPC, and medical center and hospice staff jointly attended CAPC conferences. A palliative care consult service began with voluntary attending support from the Department of Medicine and the hospice. While needs assessment progressed and administrative support was fostered, consultation progressed slowly. Within the last year, the PCCS at WFUBMC formally began with enthusiastic administrative support, including a full-time nurse coordinator and half-time support for medical direction outsourced to the hospice. Once a "face" became associated with the PCCS, the service has grown rapidly to capacity. Plans now include hiring a second nurse coordinator and additional physician resources as well as ultimate development of a palliative care unit.

The PCCS at WFUBMC demonstrates typical growth of a consult service in an academic medical center. Figure 1 demonstrates consults by month. Figure 2 shows the wide variety of services requesting palliative care consultation. While one might expect the general medical service to be the highest, it is clear that palliative care has become a regular part of ICU care. The most common reasons consultations are requested are shown in Figure 3. Communication issues such as establishing goals of care and understanding prognosis clearly lead the way. In fact, the most common interventions of the PCCS are not changes in symptom management, but family conferences. The PCCS has also demonstrated significant cost savings for WFUBMC through decreased length of stay and decreased ICU length of stay, as well as through more appropriate resource utilization. Recently an outside reviewer suggested cost savings based on the current number and type of consults per year will be at least \$1 million and are more likely to approach \$2 million.

Discussion

Palliative care is clearly more than “care from a friendly relative.” Palliative care has unabashedly adapted and adopted principles of care firmly rooted in the hospice movement and applied them to patients with advanced illnesses and their families. Palliative care services provide “specialized care through specific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services.”¹

The long list of shortcomings in end-of-life care may seem daunting. With the rapid development of palliative care services across the country, it may seem like something hospitals *should* or *must* do. Indeed, developing standards from the Joint Commission on Accreditation of Healthcare Organizations

(JCAHO) and other accrediting organizations may make it a “have to” in the near future. There is an old anonymous saying that suggests, “you can’t do everything at once, but you must do something at once.” As these two examples in Forsyth County demonstrate, it may not matter how you start, as long as you start.

There are individuals within every hospital and community who “want to” develop models and standards of care that could become palliative care services. It is important to find that core group of leaders and champions and start somewhere. A palliative care program will follow; the wheel need not be reinvented. It will become the standard of care and succeed in improving both end-of-life care and care for all seriously ill patients and their families. It may be wise to simply take a deep breath, a leap of faith, and follow the CAPC motto: “Just do it!” **NCMJ**

REFERENCES

- 1 Morrison RS, Meier DE. Palliative Care. *N Engl J Med* 2004;350:2582-90.
- 2 Hanson, LC. Palliative Care: Innovation in Care at the End of Life. *North Carolina Medical Journal* 2004;65(4):202-208.
- 3 American Board of Hospice and Palliative Medicine website. www.abhpm.org
- 4 Center to Advance Palliative Care website. www.capc.org
- 5 A Guide to Building a Hospital-Based Palliative Care Program. New York, CAPC Monograph 2004.