

## Next Gen Palliative Care

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THE U.S. HOSPICE and palliative care movement began in the 1970s when it was first recognized that care for seriously ill and dying patients was less than optimal. Phase 1 of the movement occurred in the 1970s and '80s with the growth of hospice services characterized by the rapid expansion of community hospice programs and passage of the Medicare Hospice Benefit. A failure of the movement to significantly impact hospital and academic medicine culture led to Phase 2, roughly from 1990 until now, the era of the specialist palliative care professional and hospital-based palliative care programs.<sup>1</sup> This phase has seen further expansion of hospice resources along with a robust research foundation documenting the many positive benefits of hospice and palliative care philosophy on patient care and health care utilization. I believe the time is right to push toward Phase 3, a new paradigm for our specialty, to focus our efforts on improving generalist (primary) palliative care through systems-based approaches to care.<sup>2</sup> Note, my use of the term "generalist" refers not only to physicians, but includes the primary nurse, social worker, discharge planner, chaplain, and others who provide day to day patient care services.

Although the palliative care movement has leaped forward in ways that were unimaginable just 10 years ago, it is important to examine where the movement has failed to make an impact, despite almost 40 years of work. A recent case that I was involved with on a personal level serves to illustrate the problems.

A close personal friend's frail elderly mother was hospitalized in a large southern urban medical center. A familiar slow downward spiral occurred with several trips into and out of a traditional, "cure focused" medical ICU, worsening complications, and poor communication between health care providers and the family. After 40 hospital days the patient was not decisional, on a ventilator, and heading towards renal replacement therapy. The family was exhausted, confused, and angry. The hospital had a vibrant, well-staffed palliative care program that was not involved in the patient's care. After 40 days, the family, who were very familiar with the concepts of palliative care, contacted me for advice. *Is this the time that the palliative care team should get involved? Would asking the attending physician to get palliative care involved lead to anger and possible repercussions against the family?*

All of you know this scenario and likely see variants in your hospital on a daily basis. Two features stand out; first, despite the presence of a palliative care team, they were not involved in what was clearly a patient at risk for complex unmet palliative care needs.<sup>3</sup> Second, the family, much more knowledgeable about palliative care than most, were intimidated about requesting a palliative care consultation out of fear of

alienating the attending physician. Despite the growth of consultation teams, of extensive health professional palliative care education, and positive media attention about the benefits of palliative care, we failed to impact the care of this patient. I emphasize that "we" failed this patient and family, rather than the treating physician and hospital culture, to highlight that this is our problem to fix; we can't wait for others to step in and lead efforts to improve the system of care for seriously ill patients.

As I travel the country working with hospital palliative care programs in various stages of development, I encounter many self-satisfied teams expounding on their growing volume of consults. But dig below the surface and almost all "successful" programs, not to mention struggling programs, will admit to the same chronic problems: overwhelmed and often exhausted staff; difficulty recruiting new palliative care staff and finding the funding to do so; lack of time to capture and analyze program outcomes; lack of time to pursue educational opportunities; and failure to impact pockets of patient care, including specific clinicians who "don't get it" and hospital units where palliative care principles have failed to take hold. At best the most successful teams believe they are impacting no more than 50% of hospitalized patients in need of palliative care services.

The reality is that there will never be enough *specialist* palliative care providers to meet all patient and family needs. Increasing the number of palliative care specialist staff to meet increasing clinical demand is an unsustainable, and I would argue, undesirable model of how our specialty should be developing. I will summarize this in two guiding principles:

1. Education alone will not fix the problem of poor clinical care for seriously ill patients.
  - A systems-based approach, of which education is one component, is needed to identify, assess, and manage all patients with palliative care needs.
2. Specialist palliative care teams will not be able to expand indefinitely to meet the majority of palliative care problems in their institution.
  - Improving generalist (primary) palliative care knowledge, skills, and practice behavior will be essential to improve care for the majority of patients in need.

### Changing the System

Wherever I go I hear this phrase: *If only we could get the doctors to buy in to palliative care philosophy; we just need to do a better job of education.* Education is an important tool, but not

the only tool to change practice.<sup>4-5</sup> Many years ago, when my academic focus, like many of today's palliative care senior leaders, was working to relieve cancer pain, I learned the limits of medical education. Indeed, the advances in cancer pain management over the last 20 years have not come from education, but rather from systems-based approaches to change practice including standards for patient assessment (e.g., 5th vital sign), chart documentation tools, opioid order forms, and quality improvement efforts to monitor compliance with pain standards and policies.<sup>6-8</sup> In my own hospital, by far the most important element leading to improved practice was to mandate that all clinicians use a preprinted opioid order form with defined drugs/doses/schedules. Overnight, analgesic prescribing practice became aligned with national standards in a manner that dozens of lectures and workshops on pain had failed to accomplish. The reason education fails to change pain practice is that deeply held clinician attitudes prevent application of key knowledge. Fear of addiction and drug overdose combined with cultural attitudes about who is likely to be in pain override traditional education efforts. When it comes to practice change, *attitudes trump knowledge every day.*

The lesson for palliative care is similar, where attitudes about serious illness, hospice and palliative care, and the role of clinician as healer frequently prevent basic palliative care knowledge from being applied. Fear of provoking emotion by initiating a difficult conversation, fear of peer pressure by discussing a comfort care approach, fear of lawsuit for not "doing everything": these are the attitudinal barriers which prevent timely and compassionate care for our most vulnerable patients. As with cancer pain, we must adopt systems-based approaches to improve palliative care in a manner that extends past the specialist teams of today.

I am often asked, "What do you mean by systems-based approaches?" I like to summarize systems change work using the CARES paradigm.<sup>9</sup>

**Commitment:** an institutional commitment to make fundamental changes in how care is delivered; this includes allocating staff time and resources to work towards change and developing quality improvement initiatives to ensure that changes are effective;

**Assessment:** a routine process for identification and assessment of patients in need of palliative care services;

**Education:** a robust educational program working to improve attitudes, knowledge, skills, and practice behavior;

**Responsibility:** a system in place to identify and manage outliers, patient care problems that fall through the cracks;

**Standards:** written standards, policies, checklists, and other measures that clearly define both the processes of care and the role of each health provider in providing that care.

Recent work on surgical checklists and methods to reduce catheter infections or hospital readmissions are examples of systems-based change.<sup>10-12</sup> Applying the CARES paradigm to palliative care might include: routine methods to identify and assess the at-risk patient; electronic medical record (EMR) prompts to trigger routine encounters to discuss prognosis and goals of care; standards and policies that define the role of all clinicians who interface with the at-risk patient; EMR tools that are routinely used to document symptom assessment and goals of care discussions; education efforts for all facility staff; and quality improvement initiatives to monitor key outcomes:

Was pain assessed and treated in a timely manner? Did key communication encounters occur as defined by policy and were they documented?<sup>13-16</sup>

Turning to the idea of improving generalist palliative care, I believe that as hospital palliative care programs have expanded, an unintended consequence is that we have successfully enabled generalists to avoid providing basic palliative care services. Frankly, it is easier for the generalist to call for a consult than to sit down and initiate an emotionally laden conversation. Think about your own program: What percentage of your consults are for straightforward palliative care issues, as opposed to truly complex, specialist-level issues? My experience is that easily 25%-50% of referrals are for management of generalist-level problems. A view contrary to the idea that we have enabled generalists, and one with merit, is that the mere presence of palliative care teams has helped improve generalist palliative care skills through positive role modeling. However, this process is painfully slow and random, limited to those clinicians who buy in to the philosophy of palliative care and then seek out self-improvement in formal or informal ways.

I envision Phase 3 of our movement as a time when palliative care staff lead and/or participate in system-change efforts that help foster the generalist clinician in taking greater responsibility for basic palliative care services. In parallel to the systems-change efforts described above, generalist clinicians will need competency-based education. For physicians, I would like to see this education linked to hospital credentialing, as hospitals are the key stakeholders for improving palliative care. By competency-based education I am referring to education that is grounded in generalist competencies for basic palliative care skills, competencies that require active learning opportunities and assessment with real or simulated patient encounters. Specialist palliative care clinicians can help take the lead in providing this education, provided they are willing to step away from PowerPoint as the sole means of providing education, and move to using reflective and experiential teaching methods that directly tackle the difficult attitudinal barriers that prevent application of core palliative care knowledge.<sup>17</sup>

### Transitioning to Phase 3

I've spent the last few months talking to hospital-based palliative care program clinicians across the country, trying to learn how they are envisioning their future. Most are painfully aware of their current limitations and are seeking inspiration for new models that would broaden the impact of palliative care in their institutions. One of the great aspects of our field is the willingness and courage of program leaders to experiment with changes in practice so as to impact a greater number of patients and families. I believe innovations are occurring, but slowly, and we need a push to accelerate change. I see two potential sources for the push. First, a top-down effort by institutional administrators who recognize the great potential of palliative care to positively impact basic patient care outcomes, satisfaction, readmissions, and cost and who challenge the existing palliative care teams to broaden their scope of activities. Ideally, some of this push will come from patient demand and some from positive changes in the health care reimbursement system that is working to reward more patient-centered care. Alternatively,

a bottom-up push can occur from palliative care teams that recognize there are limits to funding new team members and that have visionary leaders who can step back and realign their team's priorities with hospital priorities and as such focus on the goal of impacting all hospitalized patients in need, rather than solely on consultation volume as a marker of program success. Program leaders will need to "think outside the box," to align the strengths of their staff with hospital priorities, and, perish the thought, perhaps limit the number of specialist consultations so as to devote a portion of their resources to improving generalist palliative care through systems change efforts.

Either way, top-down, bottom-up, or ideally a combination of both, we need a change in focus to move us on a path to greater integration of palliative care principles across the spectrum of health care, not only in hospitals, but across the entire continuum of health care. I believe that now is the ideal time to push for this new focus of our specialty. We have a growing critical mass of specialists, we are likely past the tipping point of integration into hospital culture, and there is top-down urgency to reform health care in a manner that perfectly fits with hospice and palliative care philosophy: providing the right care, at the right time, for the right patient.

## References

1. Palliative Care in Hospitals Continues Rapid Growth for 10th Straight Year, According to Latest Analysis. <http://www.capc.org/news-and-events/releases/07-14-11>
2. Von Gunten CF: Secondary and tertiary palliative care in US hospitals. *JAMA* 2002;20;287:875-881.
3. Weissman DE and Meier DE: Identifying patients in need of a palliative care assessment in the hospital setting: Consensus recommendations. *J Pall Med* 2011;14:1-7.
4. Greco PJ, Eisenberg JM: Changing physicians' practices. *N Engl J Med* 1993;329:1271-1274.
5. *Organizational Change*. CAPC Campus Online. <http://campus.capc.org/>
6. Ferrell BR, Dean GE, Grant M, Coluzzi P: An institutional commitment to pain management. *J Clin Oncol* 1995;13: 2158-2165.
7. Gordon DB: Critical pathways: A road to institutionalizing pain management. *J Pain Symptom Manage* 1995;11:252-259.
8. Weissman DE, Griffie, J, Muchka S, Matson S: Building an institutional commitment to pain management in long-term care facilities. *J Pain Symptom Manage* 2000;20:35-43.
9. Weissman DE, Block SD, Blank, L, Cain J, et al: Incorporating palliative care education into the acute care hospital setting. *Academic Medicine* 1999;74:871-877.
10. Haynes AB, Weiser TG, Berry WR, Lipsitz SR: A surgical safety checklist to reduce morbidity and mortality in a global population. *Safe Surgery Saves Lives Study Group*. *N Engl J Med* 2009;360:491-499.
11. Byrnes MC, Schuerer DJ, Schallom ME, Sona CS, et al: Implementation of a mandatory checklist of protocols and objectives improves compliance with a wide range of evidence-based intensive care unit practices. *Crit Care Med* 2009;37:2775-2781.
12. Schultz MJ, Gajic O: Mandatory checklists at discharge may have the potential to prevent readmissions. *Crit Care Med* 2010;38:1226-1227.
13. Norton SA, Hogan LA, Holloway RG, Temkin-Greener H, et al: Proactive palliative care in the medical intensive care unit: Effects on length of stay for selected high-risk patients. *Crit Care Med* 2007;35:1530-1535.
14. Campbell ML, Guzman JA: A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia. *Crit Care Med* 2004;32: 1839-1843.
15. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ: Improving comfort and communication in the ICU: A practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care* 2006;15:264-271
16. McMillan TR and Hyzy RC: Bringing quality improvement into the intensive care unit. *Crit Care Med* 2007;35(2 Suppl): S59-65.
17. Oncotalk: Improving oncologists communication skills. <http://depts.washington.edu/oncotalk/>

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