

## Practical Issues in Palliative and Quality-of-Life Care

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### Abstract

Although palliative care is not new to health care or to oncology, oncologists still struggle to maximize the value of this type of care across the entire care continuum and across the patient's trajectory of illness. When we don't use what may be the best tools for the job, at the right

times in the care path, we miss opportunities to optimize patient and family coping, to limit suffering, and to ensure that our care plans are patient centered. In this article, we look at how we define palliative care and how the tools of palliative medicine can be used to enhance patient care in the outpatient oncology practice setting.

### Introduction

All too often, people—both health care professionals and lay people—associate palliative care exclusively with end-of-life and hospice care. This may be because of the high profile these types of care have and the attention they receive from the media. This association of palliative care with end-of-life and hospice care may also be generated by health care reimbursement benefit structures—particularly Medicare—that create a break or discoordination of care as a result of the selection of hospice care and concomitant deselection of continued curative treatment. As authors, we define palliative care much more broadly to include a breadth of goals and contributors, and avoid restrictive definitions.

At its broadest, palliative care is excellent symptom management and excellent patient, family, and intraprofessional communication regarding illness, hopes, goals and expectations for treatment over time, toward the goal of creating a patient-centered plan of care. It is expertise in the use of community resources, to assist in the practical aspects of patient care for serious illness as it progresses. It is team-based care, using the expertise of physicians, nurses, and social workers as the core elements of a team, although many more people participate in this endeavor: chaplains, pharmacists, mental health practitioners, financial counselors who notice and help manage financial and social burdens, front desk staff who observe family dynamics that are often unapparent to health practitioners. In more advanced settings, dietitians and fitness instructors may be helpful in focusing on quality of life across the continuum of care. In short, anyone who touches, sees, or talks to the patient or family is a member of the palliative care team.

For many oncologists, palliative care feels like second nature, as it should. Indeed, the demographics of aging, illness, and inevitable mortality mandate that all medical providers be competent in the basic skill sets of palliative medicine. The goal is not for the palliative care provider to usurp these responsibilities. Rather, the goal is to provide an additional layer of expertise in symptom management, as well as additional time for

support and counseling for patients and their families dealing with the intense stress and complexity of serious illness.

The point is that palliative care is everyday; it means taking care of patients. It cannot be contained by a Current Procedural Terminology code or an office visit. It cannot be the last tool in the shed, once we have exhausted all others. We suggest that its integration throughout cancer treatment ought to be the standard of care and offer some thoughts on how to advance such an agenda.

### Move Palliative Care Upstream

Fifty percent of all deaths annually in the United States happen in the hospital.<sup>1</sup> At the same time, studies report that at the end of life, people would prefer to not be in the hospital, to not be in pain or discomfort, to not be a burden on loved ones, and to not be sustained artificially.<sup>1</sup> There is a broad gulf between expressed desires and what really happens. We suggest that moving palliative care upstream may help bridge this gulf, but we acknowledge this is not a simple step. For us to narrow this gulf, patients and families need a better understanding of their illness progression over time and the meaning of related treatment options. They need to have time to explore and discuss important beliefs and values within this context, as a family and with their health care providers. Making this happen is difficult in the environment in which most of us work. It is certainly challenging in the midst of a crisis setting such as a hospital intensive care unit. But it can be just as problematic in a typical busy clinic day of 15-minute patient appointments, urgent patient calls, precertification requests, and pharmacy refills. Particularly in oncology, it is also difficult to enter these palliative care conversations in the context of a physician-patient compact built around “beating cancer.”

Palliative integration upstream can help with these issues, to reframe the fight and to counter the artificial and insidious messages of “fight, win, live” or “quit, lose, die.” Partnering upstream to introduce palliative interventions incrementally also affords the gift of time. This allows issues and goals-based

discussions to take place in a more controlled fashion along the illness trajectory, rather than being crammed into only a few intense days of intervention in the midst of a hospitalization crisis, followed rapidly by transition to end of life care as the only possible plan. We believe that earlier palliative integration in the illness trajectory improves the chances that the care plan eventually unfolding at the end of life will more likely match the patient's and family's expressed desires. Figure 1 outlines an example, drawn from the outpatient Palliative Care clinic at The University of Kansas, of such opportunity to integrate interventions over time.

### Consider Intraprofessional Communication Strategies in System Development

There are a variety of tools and programs that can help practices and health systems advance the success and adoption of excellent intraprofessional communication and understanding, a hallmark of the palliative care ethos. The Schwartz Center for Compassionate Healthcare provides training and implementation guidance for Schwartz Center Rounds,<sup>2</sup> a national program that brings together multidisciplinary members of the health care community for regular discussions of the challenging social and emotional aspects of caring for patients and families. The purpose of the Schwartz Center Rounds is to deepen our understanding of these issues and of the perspectives of our colleagues, to provide and receive support, and to return with renewed compassion to the patients we serve.<sup>3</sup> They are an important antidote to the sense of burnout so commonly experienced by clinical caregivers, a condition that oncologists and palliative care clinicians are certainly not immune to.<sup>4</sup> Another offering, Schwartz Center Connections, is a program to help all members of the health care team explore, repair, and avert communication lapses and build effective, compassionate relationships with patients and among care team members.

### Understand Potential Barriers to Execution

Some common barriers to implementing solid palliative care programs often include

- Poor or late timing of intervention, at time of crisis
- Framing of the palliative care team as the “stop” team, after all “go” measures have been exhausted
- Lack of shared agreement about the treatment plan among providers
- Lack of empowerment of every care team member to identify patient and family needs
- Lack of respect for complexity of relationships, among both family and providers

### Offer Professional Development Training for Front-Line Oncology Team Members

The investment in professional development training can be one of the best ways to develop a strong foundation for palliative care program success. We must do more than just tell team members they are empowered; we must train them to work within an empowered role, to help them navigate what still may be choppy waters. At the University of Kansas Hospital and Cancer Center, we have implemented extensive End of Life Nursing Education Curriculum (ELNEC) training.<sup>5,6</sup> We now have 50 nurses across the system who are certified ELNEC trainer champions. They lead efforts to educate front-line nurses, aides, social workers, and chaplains across the system and at Cancer Center sites. The goal of ELNEC in our system is to eventually train all nurses working in areas that deal with more than three deaths in a month's time.

### Normalize Palliative Care as Part of the Comprehensive Cancer Treatment Team

We need to work to develop understanding—handshakes rather than handoffs—among oncology and palliative care part-

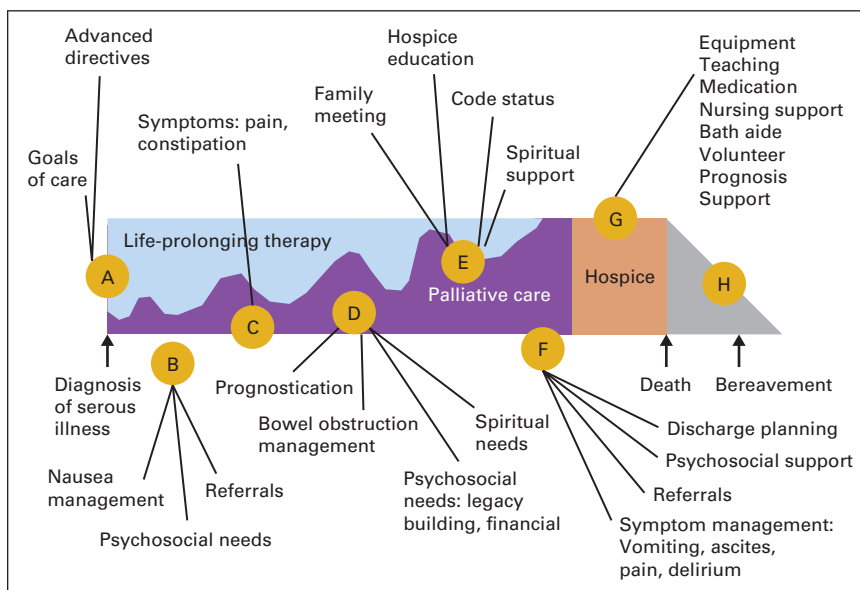


Figure 1. Example of potential palliative interventions for a patient across the care continuum.

ners, to identify upstream norms for palliative care engagement. As these comanagement relationships mature, we develop an environment for palliative care and oncology team integration for linked patient visits, close comanagement and communication fostered by dedicated palliative care space in the cancer center, proximate to the oncology provider.<sup>7</sup> This embedded, or cosituated model, allows for combined patient and family communication, early integrated interventions for symptom management, and efficient communication and follow-up regarding interventions and shifts in the plan of care. Normalizing palliative care upstream, during the active treatment phase, allows time for the optimal management of symptoms and patient-initiated discussion of fears regarding potential future outcomes, when it is not yet a crisis. These discussions can empower the patient and family to ask questions or express worries that they might otherwise not talk about, for fear that it might impact their chemotherapy plan. Upstream comanagement also shows the patient and family that their providers are partners, that they do not face abandonment by their oncology provider and that palliative care is an additional, supportive element of their comprehensive cancer treatment plan. In our practice, one oncologist has used an analogy of pilot and copilot to describe the relationship between himself as the oncologist and palliative care as his partner: “my role as your oncologist is to focus on the cancer treatment, the numbers, like all of the switches on the front of the plane. My palliative care partner helps me, and you, by concentrating on what might not be so easily seen—how all of that is affecting you—the time to listen for the hum of the plane’s engine.”

We believe that providing outstanding palliative care is not merely practical, but imperative. We believe it enhances quality of care when added to the work done by the oncology team. The strategies described here are proving successful for our outpatient palliative care program’s growth and development. We would expect the successful integrated team see fewer deaths in a hospital setting, longer hospice lengths of stay, less chemo-

therapy in the last weeks of life, and higher satisfaction levels for patients and families.<sup>8,9</sup> Adjunctive programs such as the Schwartz Center Rounds and Schwartz Center Connections provide support for all of the members of the health care team so they can sustain patients, families, themselves, and each other.

#### Authors’ Disclosures of Potential Conflicts of Interest

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