

settings of care where quality measurement should be tailored (e.g., community-based palliative care²), and 4) the care models that transition across generalist and specialist palliative care.³ Furthermore, we should expand into other important components of palliative care including transitions of care, support of caregivers, and patient and caregiver understanding of prognosis, among many others. We should be creative and rigorous in our approach, mirroring the methods from systematic research to evaluate generalizability and ability for implementation. Additionally, we should design quality measures that can inform dual goals of accountability (i.e., evaluating effectiveness of care for administrators and payers) and quality improvement (i.e., using data to inform areas for improvement) simultaneously.⁴ Moreover, we should develop the infrastructure to aggregate and compare our experiences, ultimately utilizing our collective wisdom to refine and revolutionize our best practices.

Palliative care is maturing as a discipline simultaneously with large-scale changes in accountability and reimbursement in health care. We are learning how to demonstrate our value in the language of cost avoidance⁵ and decreased hospital readmissions.⁶ We also are defining the quality and research questions that need to be answered to move our field forward. Moreover, collaborations with other membership societies and large-scale initiatives like the Virtual Learning Collaborative and Primary Palliative Care Consensus Statement between the American Academy of Hospice and Palliative Medicine and the American Society of Clinical Oncology are further defining best practices and methods for implementing those practices. These are excellent first steps to demonstrate that we, as palliative medicine professionals, take ownership of issues of quality for all who suffer with chronic and serious illnesses. Now, more than ever, the shifting winds of health care reform earmark a time where palliative care must transition from saying “we’re here” to “we’re great,” followed by one additional key phrase: “and here’s how we prove it.”

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The Bow Tie Model of 21st Century Palliative Care

To the Editor:

The World Health Organization’s definition of palliative care^{1,2} has evolved such that the recipient’s illness is no longer required to be deemed incurable. Palliative care is now described as an approach applying to “life-threatening illness” and “applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.” This modern definition aims to include patients at a stage in their illness when cure may be unlikely, but not impossible. Despite this evolution in understanding of our specialty, public perception may be lagging behind.

The benefits of early integration of palliative care are well established; however, the challenges of actually achieving early integration are, unfortunately, equally well recognized.^{3–5} Late referrals and inadequate resources are common in many palliative care programs and

limit the programs' ability to achieve maximum potential both for the relief of suffering and for medical care cost containment.⁶

Despite the benefits of early integration, in many institutions palliative care is still only resorted to when all hope of cure or disease control has been lost. This image is often perpetuated by the media and even by some health care professionals. It may be understandable, given the relatively rapid development of the specialty and only recent demonstration of the benefits (including cost savings) of maximizing palliative care early in the course of serious illness. Confusion often results from the plethora of terms used to describe the many palliative care services offered throughout the disease process, such as *supportive care*, *hospice*, and *end-of-life care*. Many programs working toward earlier integration with disease management have even changed their names because of the association of the term *palliative care* with dying.⁷

If we cannot agree on consistent terms to describe what we do, how can we expect our colleagues and potential consumers of our services to understand?

Visual models can be helpful tools to explain complex concepts and have helped advance the understanding of palliative care since the term was coined in Canada over 30 years ago. An example of a helpful visual model is the recently presented house-shaped model describing a "climate of healing" used to facilitate complex discussions around goals of care.⁸ Current visual models that aim to illustrate a gradual transition from curative intent treatment to palliative treatment are plentiful. A simple "Google pictures" search shows many versions of the horizontal, diagonally divided rectangle. Some include a tapering triangle of bereavement on the right and the diagonal line is often undulating or fuzzy.⁹ A typical example is shown in Fig. 1. These models of the relationship between palliative care and disease-modifying treatments all either show a trajectory ending in death or having no trajectory at all.¹⁰ Despite knowing at some level that they will die eventually, entering a pathway in which the only possible outcome is death is not inviting to patients and their families. If early integration of palliative care with disease management is the goal, then the possibility of cure must still be recognized when considering a referral, at least

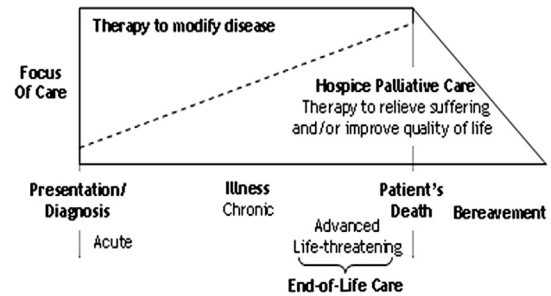


Fig. 1. Canadian Hospice Palliative Care Association model.

in the short term. If we cannot "get them in the door," much of the potential benefit of palliative care interventions could be lost. The excellent work that palliative care teams can do with patients who have difficulty accepting their own mortality, can only be done once we have contact with them.

A new model to describe palliative care is needed to acknowledge the duality of an approach that prepares patients for the worst (death) but still allows hope for the best (cure). The goal of this model would be to help people see palliative care as a normal and essential part of medical care. It would describe a process in which the possibility of dying can be gently introduced at a time when patients' and families' thoughts may be consumed by hope of cure. Therefore, I propose the following model, which adheres to the scope currently defined by the World Health Organization. As shown in Fig. 2, the model consists of two overlapping triangles resembling a bow tie, with an arrow pointing from left to right. The first triangle represents disease management and the second triangle is palliative care. The base of the palliative care triangle (end of the model) includes both death and survival as possible outcomes. The arrow indicates that this is a dynamic process with a gradual switch in focus. The key difference between this and traditional

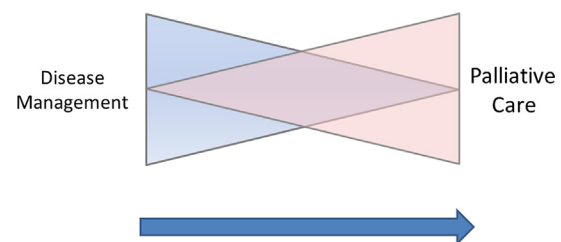


Fig. 2. Basic model of integrated palliative care.

models is that survivorship is included as a possible outcome.

The model's simplicity does not diminish its power as a communication tool, as it can be enhanced to explain complicated concepts for individual situations. The disease management triangle can be adapted for any illness. For example, it may be used to illustrate the role of supportive care interventions along with anti-cancer treatments (Fig. 3), while maintaining a visible reminder of the existence of the palliative care triangle and possibility of dying throughout. Similarly, as shown in Fig. 4, the palliative care triangle can be enhanced to illustrate where the various components of modern supportive and palliative care fit into the patient's journey. The contents of the triangle can be adapted to introduce and explain the services available and the terminology being used in the patient's particular setting. Additionally, the direction of the model can be reversed for cultures with a written language that reads from right to left. The adaptable and simple design makes it easier for care providers to generate it quickly for patients.

The brief examples shown here should not be seen as excluding any of the other vital aspects of palliative care, including psychological, spiritual and social support, advance care planning, music and art therapy, physiotherapy, respiratory therapy, etc. As with the myriad of available disease-modifying treatments, the many types of palliative care interventions are too numerous to list, but all interventions can be placed in one of the model's spaces. The labels can be added by the user to create a care map tailored to an individual patient's circumstances and needs. The map for a patient with chronic obstructive pulmonary disease may have very different labels than those of a cancer patient, but the anchor umbrella terms of *Disease Management* and *Palliative Care* include all kinds of services. This

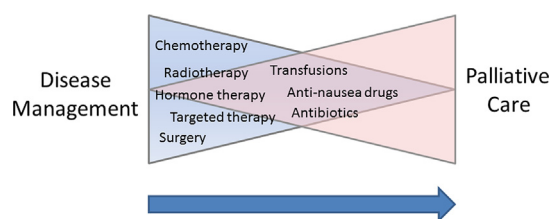


Fig. 3. Disease management-enhanced model.

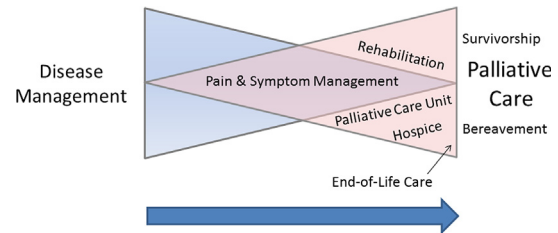


Fig. 4. Palliative care-enhanced model.

model is not meant to imply that all palliative care teams and hospices should provide rehabilitation and survivorship support. Its function is to show patients that these services are included as possible components of their care in the future and simplifies the language commonly used in medicine.

The word *survivorship* is most often understood to describe the state of being that follows only successful disease-targeted interventions, such as elimination of detectable cancer or following successful organ transplantation. However, as a medical term, it is starting to be used in reference to a type of service overlapping with or including palliative care, with widespread disagreement on the actual meaning. Survivorship is used here in its common form, as defined by the Oxford Dictionary: “a person who survives, especially a person remaining alive after an event in which others have died.” It also is used to introduce the concept of using the term in reference to a type of service included as a palliative care intervention targeting quality of life but different than hospice or end-of-life care.

This model permits the early acceptance of a care pathway where the two approaches to care are integrated from the time of diagnosis, when the ultimate outcome (death or survivorship) may be too frightening for the patient to contemplate. My intention in communicating this “bow tie model” is to facilitate earlier acceptance of the role for palliative care for people diagnosed with serious illness, whether fatal or not. It would thereby maximize the proportion of time that people would benefit from the wide variety of palliative care interventions available. The model allows for an exit strategy other than death and facilitates early introduction of palliative care at a time when misconceptions and confusion in terminology may block access on both sides of the patient/caregiver partnership.

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Serial Prognostication: A New Look at an Old Tool

To the Editor:

We read the article by Arai et al. with interest.¹ The authors conducted a retrospective study to examine the association between a change in the Palliative Prognostic Index (PPI) and survival in 374 cancer patients admitted to a palliative care unit in Japan. In multivariate analysis, they found a highly significant association between PPI change and survival (hazard ratio 6.6 per point increase in PPI; 95% CI, 4.9–9), independent of baseline PPI scores. This study suggests that the PPI is not only a prognostic tool but one that is sensitive to change, and importantly, the degree of change has prognostic utility.

Some additional information would help readers appreciate the significance of their findings. The PPI comprises five variables: the Palliative Performance Scale score, oral intake, dyspnea, delirium, and edema.² It would be useful to know the breakdown of PPI scores on admission and at follow-up. Did some of the PPI variables change more than others? Were some of the variables stable over this time period? Based on the data provided, the magnitude of PPI change appeared to be small (median = 0; interquartile range, 0–0.57). A better understanding of how the PPI evolves over time may facilitate future research in this area.

How the PPI data were collected also could have a major impact on the interpretation of study findings. Specifically, more information on the physician(s) who collected the data, and how each variable was assessed, would be crucial. How was dyspnea assessed especially in the context of delirium? Finally, because the PPI was assessed in the presence of other physiologic changes (e.g., death rattle), a prospective study adjusting for other prognostic variables would be needed.

The timing of the second data point raises some important questions. It would be helpful to learn how the authors decided that the PPI should be repeated five to seven days later, and if any exploratory analysis was done to examine the optimal timing related to a change in the PPI. We wonder if a shorter interval would have similar discriminatory power