

Early palliative care: taking ownership and creating the conditions

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The evidence for early integration of palliative care into standard oncology care is growing. All things considered, the benefits to patients, families, and the health care system of initiating palliative care earlier in the illness trajectory and not relegating it to the terminal phase in the last days or weeks of life far outweigh any potential burdens. Kain and Eisenhauer, in this edition of *Current Oncology*, add a noteworthy voice to the call for action. Notably, that call is neither new nor confined to cancer care; the need to provide palliative care and to initiate it earlier in the illness trajectory is echoing ever louder, to include many non-cancer conditions ranging from advanced heart, lung, liver, renal, and neurologic diseases to conditions such as dementia and frailty¹⁻⁴.

In 2002, the World Health Organization modified its definition of “palliative care” by replacing the term “terminal illnesses” with “life-threatening illnesses.” This intentional alteration emphasizes the need to implement palliative care earlier in the illness trajectory. That same year, the Canadian Hospice Palliative Care Association embraced the approach, embedding it in its model in which palliative care starts earlier, alongside treatments to control the disease and manage its complications. When the disease progresses and disease-modifying treatments become less effective, the palliative care approach starts to take more prominence. The two approaches are therefore complementary in a dynamic process rather than mutually exclusive, as in the “old” model in which palliative care was considered only in the terminal, end-of-life phase.

Identifying and addressing physical, psychological, social, and spiritual needs should not be confined to the terminal phase of disease and neither should advance care planning. Patients whose diseases are potentially controllable or even curable also benefit from a supportive and palliative care approach that aims to assist quality of life. Likewise, recognizing disease progression and engaging in honest goals-of-care discussions accompanied by wise treatment choices in a way that promotes realistic hope and prepares for future possibilities should not be relegated only to end of life.

Hawley⁵ has adapted the Canadian Hospice Palliative Care Association model in what is called the “bow-tie” model (Figure 1). It, too, emphasizes the complementary nature of disease-modifying treatments and palliative care. Unfortunately, however, the model relegates palliative care units to end-of-life care. In many parts of Canada and internationally, admissions to palliative care units are not

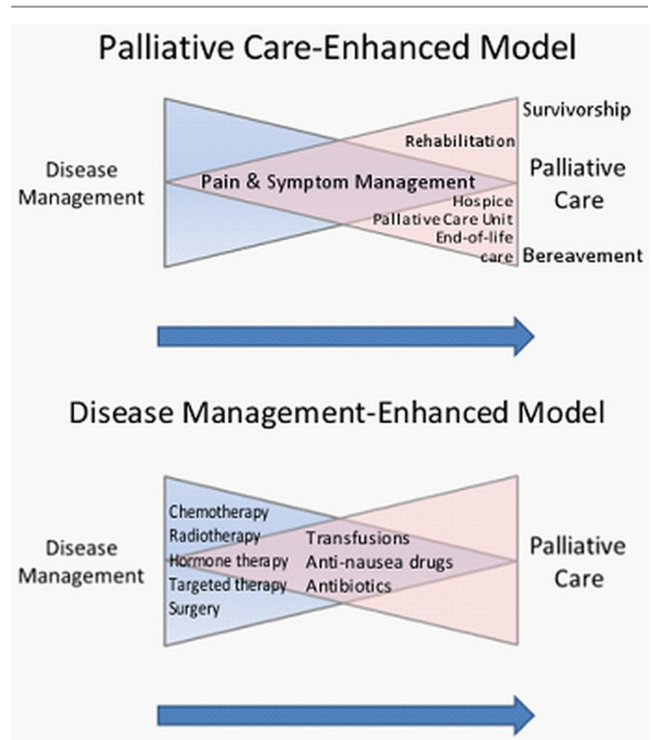


FIGURE 1 The “bow-tie” model emphasizes the complementary nature of disease-modifying treatments and palliative care.

limited to end-of-life patients, but are open to patients with complex symptomatic and psychosocial needs across the illness trajectory; on the other hand, residential hospices generally provide end-of-life care. Of particular note in the “bow-tie” model is that it accommodates rehabilitation and survivorship. Palliative care rehabilitation programs for patients with palliative care needs who are not at end of life have highlighted the “early” palliative care model and its accompanying benefits, particularly through maintenance of functional status, mobility, and quality of life⁶.

Whose responsibility is it, then, to provide palliative care? Kain and Eisenhauer appropriately highlight the need, across Canada, for more specialist palliative care resources to address current gaps and future needs. Ontario, for example, has 218 medical oncologists and 225 radiation oncologists⁷. It has only 276 “palliative care” physicians—too few to provide all the palliative care

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required for cancer and non-cancer patients⁸. Some hospitals in Ontario have inadequate specialist palliative care physician or nurse coverage (and in some cases none at all). Shortages of palliative care physicians or inadequate funding account for that lack. The Champlain region (1.3 million population and 30,000 km²) in southeastern Ontario, which includes Ottawa, has a 1.0 full-time equivalent palliative care physician positions in its community palliative care consultation team. In contrast, the Edmonton region in Alberta, similar in population size and area, has a much more appropriate complement of 5 full-time physician equivalents and 5 full-time nurse equivalent positions. Other Ontario community teams have no physicians, because those teams are funded as nurse-only models by the Ontario Ministry of Health and Long-Term Care (MOHLTC).

Advocacy efforts to the MOHLTC, Cancer Care Ontario, and the Ontario Medical Association to address the gaps have, with some exceptions, generated few concrete results in recent years. In 2013 for example, Cancer Care Ontario opted to exclude palliative care physicians from the provincial alternative funding plan for cancer care specialists negotiated as part of its Models of Care initiative. The MOHLTC provides hospital on-call funding for some hospital-based palliative care teams, but not for others. The praiseworthy decision by the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada to recognize palliative medicine as a subspecialty will likely increase interest in the field, but the insufficient number of palliative care residency and physician positions in Ontario could create bottlenecks. Bold action by policymakers, health services administrators, and educators is needed to overcome those funding and resource barriers.

However, even with much-needed increases in the palliative care specialist workforce (and the administrative support that is often lacking in many centres), this relatively small workforce will not be able to provide for all the palliative care needs (including early integration) for all patients with life-limiting cancer and non-cancer diagnoses. The responsibility for providing palliative care is not solely that of palliative care specialists or specialist teams, it is everyone's business. All health care professionals who provide any form of care to patients with life-threatening cancer and non-cancer illnesses—including oncologists, family physicians, internists, and cardiologists, to name only a few—should take ownership of the challenge by providing a palliative care approach to their patients. "Palliative care approach" refers to primary-level (that is, generalist-level), high-quality palliative care that could be provided by health care professionals who are not palliative care specialists.

For several years now, the American Society of Clinical Oncology has endorsed that approach, and more recently, it further elucidated the competencies that the generalist-level palliative care for oncologists and cancer care providers should include⁹. A case has also been made for a palliative care approach to be provided by family physicians¹⁰. Most oncologists and oncology nurses acknowledge a role in providing the palliative care approach to their patients¹¹. Cancer Care Ontario has developed a care pathway that integrates the palliative care approach and psychosocial care in everyday cancer care¹². Gardiner *et al.*¹³ outlined

the important role for generalist providers (including oncologists and clinicians in many different specialty areas and in family medicine) in the earlier incorporation of palliative care and transitions to palliative care.

Apart from increasing access to palliative care, other benefits accrue when attending non-palliative-care clinicians provide a palliative care approach to their own patients. They often have close rapport with their patients and are trusted by the patients and families. Continuity of care is valued by palliative care patients¹⁴. Leaving it up to a third party, particularly the palliative care team, to disclose bad news and to discuss goals of care in the presence of disease progression or to initiate advance care planning might leave the patient feeling abandoned and the palliative care clinician feeling vilified as the harbinger of doom. Many palliative care clinicians can share experiences of being fired by patients and families whose diseases have progressed, but who were not fully informed of the situation by their attending clinicians.

Several conditions have to be met for non-palliative-care providers such as oncologists, oncology nurses, and family physicians to effectively provide a palliative care approach to their patients. Those conditions include education, support, tools, and incentives and supporting policies. Many health professionals have not received adequate basic palliative care training and feel uncomfortable and ill equipped to provide such care¹⁵. A survey of hospital-based staff reported that 19.3% of staff time was spent caring for end-of-life patients, but that only 19% of respondents had received formal palliative care training¹⁶. Almost three quarters wanted formal training in the area and perceived that confidence in palliative care delivery was significantly greater for the staff with formal palliative care training. The palliative care approach should be an integral component of undergraduate, postgraduate, and continuing professional development curricula. Some standardized programs are available in Canada for these purposes, including Pallium Canada's LEAP (Learning Essential Approaches to Palliative Care) courses (inter-professional), the Educating Physicians on End-of-Life Care course and other intensive interprofessional courses offered by McMaster University (Victoria Hospice), as well as Life and Death Matters (for support workers).

Hospital and community settings should have adequately staffed specialist palliative care teams to provide support with complex patients, to verify care plans when needed, and to take over the care of the small proportion of cases that are extremely challenging. A recent systematic review of the impact of hospital-based palliative care consultation teams in which the partnership model was typically used showed improvements in patient care and cost savings¹⁷. Several community benefits have been noted as well. For example, Kain and Eisenhauer quote a study by Seow *et al.*¹⁸ of the impact of community-based specialist palliative care teams in Ontario. In that work, 2 of the 11 teams studied used a consultation or shared-care model in which family physicians and community nurses provided the palliative care with the support of specialist palliative care teams. Those 2 teams achieved benefits similar to those achieved by the other teams, whose members largely used a specialist takeover model; significant reductions in

emergency department visits, hospitalizations, and hospital deaths were observed. Other studies have reported similar results using the “partnership” model between non-palliative-care clinicians and palliative care specialists^{19,20}. Funding models that undermine this consultation support role should be replaced with models and funding incentives that support it. In Ontario, for example, the absence of an adequate alternative salary-type funding plan for palliative care physicians by the MOHLTC is pushing more palliative care physicians to a fee-for-service model, which could ultimately undermine capacity-building for a primary-level palliative care approach as palliative care physicians intentionally or unintentionally take over all the palliative care, including primary-level palliative care.

A large dose of self-awareness and acknowledgment of competency limitations is also required. Oncologists and other non-palliative-care specialist providers should acknowledge their skill gaps in this area and seek programs to address those gaps. The organizations they work for should provide opportunities to acquire the necessary skills, and other incentives should be put in place. Timely referrals to specialist palliative care teams should be provided when patients require specialist-level palliative care interventions. Guidelines to assist in identifying such situations have been published²¹.

It requires commitment to participate in education programs to update one’s palliative care approach skills. By the same token, palliative care physicians require a substantial dose of humility and respect for the work done by non-palliative-care specialists and should see referrals as opportunities for support and collaboration. We are all in this together, and the article by Kain and Eisenhauer brings to the fore the need for effective collaboration and integration to improve patient outcomes.

Kain and Eisenhauer identify the “surprise question” as a useful tool. Its utility as an approach for the earlier identification of patients who could benefit from a palliative care approach has been demonstrated in various settings for cancer and non-cancer diagnoses. However, it is important to note that the “surprise question” neither limits palliative care to the last year of life nor acts as a prognostication tool. It is simply a useful alert that helps in moving palliative care upstream. Other tools to identify patients with palliative care needs have been reported and tested in various settings. Weissman *et al.*²⁰ highlighted the usefulness of tools to screen patients for unmet palliative care needs, combined with education initiatives and other system-change work. They go on to posit that hospital staff engaged in day-to-day patient care can identify and address most such needs, reserving specialty palliative care services for more complex problems²⁰.

That focus on palliation in day-to-day care in turn raises a question: What percentage of patients should be referred to a specialist palliative care service? Clearly, 100% would not be realistic, but too-small numbers would also raise concerns, particularly in the absence of the conditions already described²². In a population-based survey in Belgium²³, palliative care services were not used for 79% of patients with organ failure, 64% with dementia, and 44% with cancer. Among the most common reasons for not referring to a palliative care service was the perception

by some clinicians that they had already provided sufficient palliative care (raising the question of whether the clinicians had been prepared to provide a palliative care approach) and that insufficient time to initiate palliative care was available (indicating that palliation was being considered too late). For patients who were referred, the timing of referral varied from a median of 6 days before death (organ failure) to 16 days (cancer). Further studies are needed to determine what an acceptable range would be if all the conditions were to be in place.

Kain and Eisenhauer highlight the challenges related to the fear associated with the term “palliative care.” Cherny²⁴ summarized three different approaches to the concerns about the name. They can be summarized as “getting over it,” “living with it,” and “getting around it.” In the “getting over it” approach, the term “palliative” continues to be used, but patients, colleagues, and the public are educated about what it actually means. In the “living with it approach,” a term such as “supportive care” is used to refer to palliative care earlier in the illness trajectory and “palliative” is reserved for end of life, when the word might be less threatening for some. In the “getting around it” approach, the term is replaced with another term such as “supportive care,” “pain and symptom management,” or “quality of life.” We are concerned about the latter term, because it might simply introduce a euphemism that allows people to avoid talking about the issues and realities at hand. In any case, the measure is a temporary one, because, within a generation or less, the new word will come to acquire the same stigma as “palliative care” bears now so long as there is no education and open dialogue about what palliative care actually is. We are of the opinion that the second approach, calling a service “supportive and palliative care,” is the optimal pragmatic approach.

The language used is important. For example, confusion does arise because “palliative care” refers both to an approach to care and to a specialized care team. All patients with life-threatening illness should receive palliative care as an approach to care, but, as posited earlier in this article, that approach does not always have to be provided by specialized physicians or teams. The specific words used are also indications of the culture that exists. The phrases “the patient is not palliative yet” or “the patient is now palliative” are often used in everyday care, and yet they are inappropriate in a new paradigm in which a palliative care approach has to start earlier, because they suggest that palliative care is confined to the end of life. Phrases such as “this patient would also benefit from a palliative care approach” or “this patient now needs end-of-life palliative care” would be more appropriate.

To summarize, a paradigm shift is needed. The call is not new, but the emerging evidence for initiating palliative care earlier and more broadly is ever more compelling. The required culture change requires ownership by and collaboration between many stakeholders, including health care professionals who are not palliative care specialists, palliative care specialists, administrators, policymakers, funders, and educators. Kain and Eisenhauer make several important recommendations, including implementation of quality improvement initiatives across many care settings to achieve the paradigm shift. Cancer Care Ontario’s

INTEGRATE project is one such quality improvement initiative, as is the Speak Up campaign (<http://www.advancecareplanning.ca>)²⁵. Future studies to gather more evidence about the impact of the early palliative care model provided by non-palliative-care clinicians will be needed.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare the following interests: JP is Scientific Officer at Pallium Canada, a nonprofit organization that has been funded largely by Health Canada to provide palliative care education. MRC has no conflicts to declare.

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REFERENCES

- Gomes B. Palliative care: if it makes a difference, why wait? *J Clin Oncol* 2015;33:1420–1.
- Hupcey JE, Penrod J, Fogg J. Heart failure and palliative care: implications in practice. *J Palliat Med* 2009;12:531–6.
- Hardin KA, Meyers F, Louie S. Integrating palliative care in severe chronic obstructive lung disease. *COPD* 2008;5:207–20.
- Thoonsen B, Engels Y, van Rijswijk E, et al. Early identification of palliative care patients in general practice: development of the Radboud indicators for palliative care needs (RADPAC). *Br J Gen Pract* 2012;62:e625–31.
- Hawley PH. The bow tie model of 21st century palliative care. *J Pain Symptom Manage* 2014;47:e2–5.
- Chasen MR, Feldstain A, Gravelle D, MacDonald N, Pereira J. An interprofessional palliative care oncology rehabilitation program: effects of functions and predictors of program completion. *Curr Oncol* 2013;20:301–9.
- Canadian Medical Association (CMA). Basic physician facts [Web page]. Ottawa, ON: CMA; 2016. [Available at <https://www.cma.ca/En/Pages/basic-physician-facts.aspx>; cited 1 September 2016]
- Barbera L, Hwee J, Klinger C, Jembere N, Seow H, Pereira J. Identification of the physician workforce providing palliative care in Ontario using administrative claims data. *CMAJ Open* 2015;3:e292–8.
- Shadd JD, Burge F, Stajduhar KI, Cohen ER, Kelley ML, Pesut B. Defining and measuring a palliative approach in primary care. *Can Fam Physician* 2013;59:1149–50.
- Pereira JL, Chasen MR, Molloy S, et al. Cancer care professionals' attitudes toward Systematic Standardized Symptom Assessment and the Edmonton Symptom Assessment System after large-scale population-based implementation in Ontario, Canada. *J Pain Symptom Manage* 2016;51:662–672.e8.
- Hoffman MA, Raftopoulos H, Roy R. Oncologists as primary palliative care providers. *J Clin Oncol* 2012;30:2801–2.
- Cancer Care Ontario (cco). *Psychosocial and Palliative Care Pathway*. Ver. 2013.01. Toronto, ON: cco; 2013. [Available online at: <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=298466>; cited 1 September 2016]
- Gardiner C, Ingleton C, Gott M, Ryan T. Exploring the transition from curative care to palliative care: a systematic review of the literature. *BMJ Support Palliat Care* 2011;1:56–63.
- Michiels E, Deschepper R, Van Der Kelen G, et al. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. *Palliat Med* 2007;21:409–15.
- Osborn R, Moulds D, Schneider EC, et al. Primary care physicians in ten countries report challenges caring for patients with complex health needs. *Health Aff (Millwood)* 2015;34:2104–12.
- Frey R, Gott M, Raphael D, et al. Clinical staff perceptions of palliative care related quality of care, service access, education and training needs and delivery confidence in an acute hospital setting. *BMJ Support Palliat Care* 2014;4:381–9.
- May P, Charles N, Morrison SR. Economic impact of hospital inpatient palliative care consultation: review of current evidence and directions for future research. *J Pall Med* 2014;17:1054–63.
- Seow H, Brazil K, Sussman J, et al. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. *BMJ* 2014;348:g3496.
- Neergaard MA, Vedsted P, Olesen F, Sokolowski I, Jensen AB, Søndergaard J. Associations between home death and GP involvement in palliative cancer care. *Br J Gen Pract* 2009;59:671–7.
- Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: a consensus report from the Center to Advance Palliative Care. *J Palliat Med* 2011;14:17–23.
- Thoonsen B, Gerritzen SH, Vissers KC, et al. Training general practitioners contributes to the identification of palliative patients and to multidimensional care provision: secondary outcomes of an RCT. *BMJ Support Palliat Care*. 2016; [Epub ahead of print].
- Beauverd MA, Foley RA, Rossi I, Pereira J. Description of a tertiary Swiss university hospital palliative population based on the International Classification of Disease (ICD): a retrospective pilot study. *J Palliat Med* 2011;14:77–81.
- Beemaert K, Delines L, Pardon K, et al. What are physicians' reasons for not referring people with life-limiting illnesses to specialist palliative care services? A nationwide survey. *PLoS One* 2015;10:e0137251.
- Cherny N. Stigma associated with "palliative care": getting around it or getting over it. *Cancer* 2009;115:1808–12.
- Evans JM, Matheson G, Buchman S, et al. Integrating cancer care beyond the hospital and across the cancer pathway: a patient-centred approach. *Healthc Q* 2015;17:28–31.