



Palliative Care: Background

OMA's End of Life Care Strategy

April 2014



Background

Palliative care is a relatively new sub-specialty of medicine. The term “palliative care” was coined by Dr. Balfour Mount, a Canadian surgical oncologist (at the time) in 1973. Dr. Mount was asked to chair a panel on Elisabeth Kubler-Ross’ book: *On Death and Dying* in January 1973 at the Royal Victoria hospital in Montreal. The stories of extreme suffering described in the book were met with some scepticism by the physicians in the audience and on the panel. So Dr. Mount found some funding from McGill University to investigate care of the dying at the Royal Vic, considered one of the leading teaching hospitals in North America. The survey included case narratives of the unnecessary suffering of the terminally ill and their family members. There was “abysmal inadequacy in the control of pain and all other symptoms” and no knowledge of the suffering by the medical staff.

Dr. Mount, shocked by the findings, visited St. Christopher’s Hospice in England in September 1973. St Christopher’s was founded in 1967 by Dame Cicely Saunders. The hospice took a holistic approach to the physical, psychological and spiritual needs of its patients. Impressed by what he learnt working with Dame Saunders, Dr. Mount decided to create a hospice-like ward at the Royal Victoria. He devised a pilot project that included a hospital ward for the dying, a consultation team to work with other wards, a home-care outreach program and a bereavement follow-up program. Once the program overcame criticisms that it was “too soft” and “a waste of money”, Dr. Mount had to decide what to call the new ward. He decided against hospice, his first choice, because hospice in French means Nursing home and called the new program palliative care, based on the word *palate’s* etymology. In Latin, *Pallium* means to mitigate or to improve the quality of. The launch of the program marked the entry of “palliative care” into its modern usage. By 1976, the hospital considered the palliative care program invaluable and it became a permanent fixture at the Royal Vic. Dr. Mount, at the end of the 70s, left his career as a surgeon to devote himself full-time to the emerging field of palliative medicine and remains a passionate advocate today for palliative care.

Forty years after Dr. Mount introduced palliative care to Canada, the Royal College of Physicians and Surgeons of Canada recognized palliative medicine as a new sub-specialty of medicine (October 2013). Palliative physicians, prior to this, either took their training elsewhere or added a year of palliative residency to their studies.

OMA Definitions

Palliative care, historically, meant care provided in the last weeks or months of life to manage symptoms and provide comfort. Now, interdisciplinary care focuses on relief of pain and other symptoms including the physical, psychological, social and spiritual varieties. It supports the best possible quality of life for patients with serious illness and their families. It is appropriate at the point of diagnosis of a serious illness and creates a positive experience to replace suffering and pain in order to provide dignity at the end of life. Palliative care is appropriate even when patients are pursuing cure focused medicine; it affirms life and regards dying as a normal process.

The delivery of palliative care is based on the philosophy of the *palliative approach*. Essential components of palliative approach include:

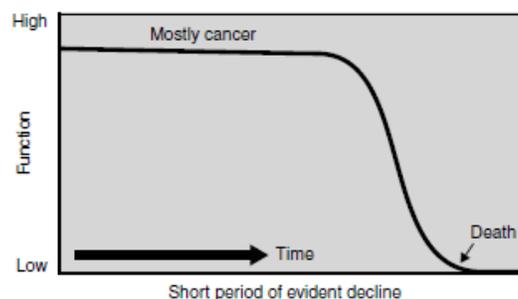
- Identify patients who would benefit from a palliative care approach earlier in their illness
- Discuss prognosis and goals of care with these patients and families—at some point need to discuss meaning of “family”
- Initiate Advance Care Planning discussions
- Assessing and managing physical and psychological symptoms at a basic level
- Identifying social and spiritual needs
- Connecting patients with palliative care and end-of-life care (EOLC) resources as needed
- Consulting and referring to specialist level palliative care clinicians and services if they need assistance because the complexity of patients’ needs and circumstances

A *palliative patient* is a patient who has been diagnosed with an advanced, progressive life-limiting disease. Two decades ago palliative care was mainly confined to the treatment of pain and other symptoms caused by cancer. Even today, 85% of hospice beds in Ontario are occupied by cancer patients. But the definition of a palliative patient has expanded to include those with chronic, deteriorating diseases such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD) and cognitive impairment. *Frailty* is the fragility of multiple body systems as their customary reserves diminish with age and disease. Frailty may already be a major path through the end of life, but the standard classifications of illness often fail to recognize it. Therefore, persons in a general state of decline are often misleadingly labeled with “heart failure” or some other specific manifestation of their more general decline. fatal chronic conditions are those that occur when the rest of the body’s systems have substantial reserves. In contrast, frailty is a fatal chronic condition in which all of the body’s systems have little reserve and small upsets cause cascading health problems.

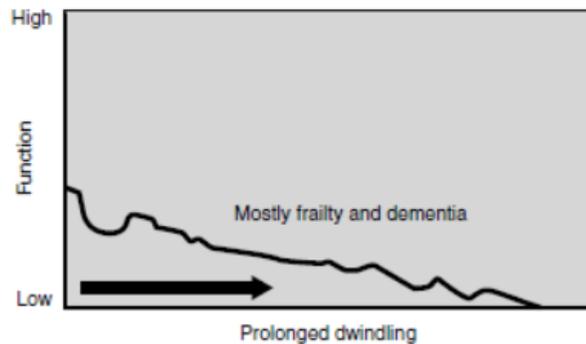
Patient Population

Changing causes of deaths and demographics have changed the picture of the palliative population. The prevalence for cancers in Ontario fell (by 5%) in 2003 from 2001, but the prevalence increased for COPD, arthritis and type 2 diabetes—mainly because people are living longer.

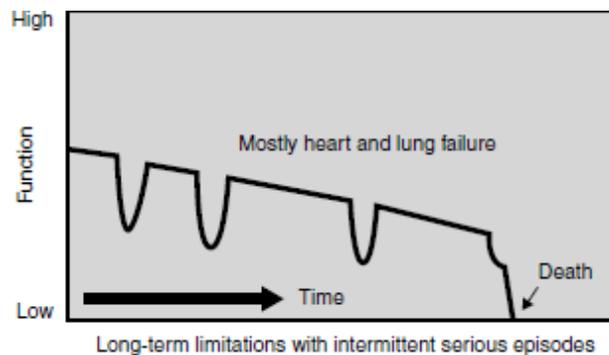
The disease trajectories are very different for the sub-groups of palliative patients. Each trajectory corresponds to a different rhythm and set of priorities in care.



- **Short period of evident decline—typical of cancer.** Most patients with malignancies maintain comfort and functioning for a substantial period. However, once the illness becomes overwhelming, the patient’s status usually declines quite rapidly in the final weeks and days preceding death. Hospice is an important part of the care for this trajectory.



- **Prolonged dwindling—typical of dementia, disabling stroke, and frailty.** Those who escape cancer and organ system failure are likely to die at older ages of either neurological failure (such as Alzheimer’s or other dementia) or generalized frailty of multiple body systems. Supportive services at home, like Meals on Wheels and home health aides, then institutional long-term care facilities are central to good care for this trajectory.

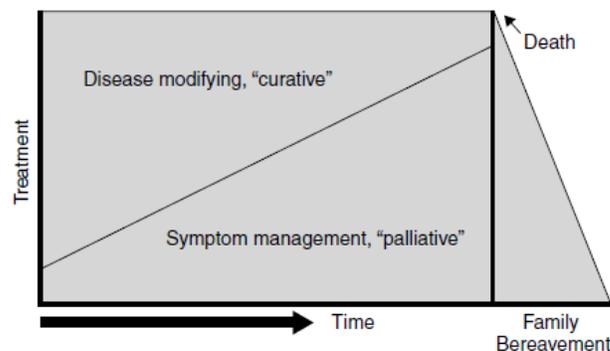


- **Long-term limitations with intermittent exacerbations and sudden dying—typical of organ system failure.** Patients in this category often live for a relatively long time and may have only minor limitations in everyday life. From time to time, some physiological stress overwhelms the body’s reserves and leads to a worsening of serious symptoms. Patients survive a few such episodes but then die from a complication or exacerbation, often rather suddenly. Ongoing disease management, advance-care planning, and mobilizing services to the home are key to optimal care. ^a

^a Lynn J, Forlini JH. “Serious and Complex Illness” in Quality Improvement

In Ontario, about 30% of all deaths are due to cancer while chronic diseases account for another 30% and 10% are due to sudden deaths. Deaths due to frailty are classified as a chronic condition or cancer since there is no code for old age or multiple organ failure. But an analysis of Medicare claims in the States showed that about 40% of all deaths are actually due to frailty.^b

Research has shown that palliative care patients realize significant benefits from care provided earlier in the disease trajectory. A recent study at Princess Margaret Hospital^c in Toronto for patient with advanced cancer showed promising findings that quality of life is improved with earlier palliative care. Other studies published after the PMH study found that patients randomized to the earlier group had better quality of life and mood.^{de} These studies support earlier involvement of palliative care teams with patients with advance, life-limiting illnesses. The new model of palliative care supports earlier involvement. The figure below depicts the new model of palliative care.



What matters most in care delivery to patients at the end of life? A large-scale study of over 400 patients and 160 family members in five hospitals across Canada^f revealed that the elements given highest priority by the patients were:

- *To have trust and confidence in the doctors looking after you (55.8%)*
- *Avoidance of unwanted life support (55.7%)*
- *Effective communication and continuity of care by your doctor (44.1%)*
- *To complete things and prepare for life's end (43.9%)*

and Policy Reform for End-of-Life Care, *J Gen Intern Med*, Vol. 16, No. 5, 2001, pp. 315–319.

^bLunney JR, Lynn J, Hogan C. Profiles of Older Medicare Decedents, *J Am Geriatr Soc*, Vol. 50, No. 6, 2002, pp. 1108–1112

^c Zimmermann C, Swami N et al. Early palliative care for patients with advanced cancer: a cluster-randomised trial. *The Lancet* February 2014.

^d Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA* 2009; **302**: 741–49.

^e Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010; **363**: 733–42.

^f Heyland DK et al. What Matters Most in End of Life Care: perceptions of seriously ill patients and their family members, *CMAJ* 2006;174(5)

Current Delivery System

Data from 2010 indicates that seniors account for 75% of deaths in Canada^g; many have multiple chronic conditions. In 2007/08, 345,327 acute care beds and 95,018 Alternate Level of Care (ALC) bed days were occupied by patients with a palliative diagnosis. In Ontario, for those persons admitted to hospital with a primary diagnosis of palliative, 73% (6927) died in hospital.

(Today, both the LHINs and the CCACs provide palliative nursing care so that palliative care services in some regions are somewhat fragmented.). It is very difficult to determine service capacity since data is not kept on the number of palliative care beds in each region or the province, number of providers or number of palliative care services in-hospital or the community. The OMA calculates that there are approximately 150-250 palliative medicine specialists with an additional 200 family physicians who provide mostly palliative care in their practice. ICES estimates that there are about 500 physicians in Ontario providing mostly palliative care in their practice, using a slightly different formula than the OMA. Cancer Care Ontario (CCO) is undertaking a much-needed capacity assessment which, we hope, will provide a useful platform for system planning.

It appears there may be a misperception by physicians that providing palliative care does not bring adequate compensation. Most palliative specialists are reimbursed through an alternate funding plan (AFP) which is negotiated between the OMA and the MOHLTC when developing a new Physicians Services Agreement (PSA). Family physicians may not know how to bill the appropriate fee codes for palliative care as, if billed correctly, the OHIP Schedule of Benefits does provide generous compensation for provision of palliative care. One of the initiatives the OMA is planning for implementation of the EOLC Strategy is billing seminars for palliative care.

Another initiative negotiated in the 2012 PSA which will improve 24/7 access to palliative services in the community is the Community Palliative on Call Program (CPOC). Applications were invited by the Ministry and the OMA in January 2014. And details of the program are available on the OMA members' website

In 2010, a tri-partite committee chaired by the LHINs, MOHLTC and the Ontario College of Family Physicians came together, working with over 80 participants from all sectors and regions of the province to develop a provincial vision for high-quality palliative care. The result was the release of the document: *Advancing High Quality, High Value Palliative Care in Ontario: Declaration of Partnership and Commitment to Action* in December 2011.

Despite enhanced funding from the MOHLTC since 2005, and the work done for the *Declaration of Partnerships* document, there still remain a number of service gaps in palliative care in Ontario and across Canada. The following table identifies service gaps^h:

^g Carstairs 2010.

^h Heyland DK, Lavery JV, Tranmer JE, Shortt SE, Taylor SJ. Dying in Canada: is it an institutionalized, technologically supported experience? *J Palliat Care* 2000;16(Suppl):S10-6.

Service Gaps in Current Practice

Type of Gap	Description
Access	<ul style="list-style-type: none"> • Lack of early identification of palliative patients • Persistent lack of dedicated coordinators/navigators to oversee best practices across care sectors; • Lack of sufficient expert medical palliative care resources to assist family physicians with provision of care (Timely access)
Assessment	<ul style="list-style-type: none"> • Lack of appropriate tools that allow family physicians to provide best practices in home and community settings
Care	<ul style="list-style-type: none"> • Lack of skilled psychosocial, spiritual, and bereavement supports for EOL patients and families living in these communities • Lack of timely respite care, necessitating unwanted and undesirable hospital admissions and emergency room visits • Lack of timely communication and flow of information in a manner that allows family physicians to remain the key providers of continuous care • Lack of mechanisms that allow family physicians, in the context of their own office “teams,” to interact and collaborate directly with community palliative care team providers
Education and decision supports	<ul style="list-style-type: none"> • Inability to model comprehensive palliative care, including best practice skills, knowledge, behaviour, and resources, for medical students and family medicine residents, owing to lack of structured contacts and resources • Lack of opportunities for practice-based continuing education utilizing academic detailing to develop best practices and collaborative skills • Lack of opportunities and resources (eg, salary replacement dollars) for mentorship, role modeling, and development of family physician practice “leads” who can be trained in turn

Shared Care Model

The OMA supports the population-based shared care model used to great success in both the United Kingdom and Australia. In the context of an aging population, an increase in life expectancy, a rising prevalence of cancer and chronic illness and scarce hospital resources there is an urgent need to support family physicians to provide effective palliative care through the shared care model.

The overall goal of the shared care model is to enhance family physician capacity to deliver palliative home care through collaboration with an interprofessional palliative care team, usually consisting of an advanced practice nurse (APN), a palliative medicine physician and a psychosocial/spiritual advisor and/ or bereavement counsellor. Family physicians remain most

responsible for their patients, with the Palliative Care Team (PCT) involved as collaborating in care and second-line support. Communication between the family physicians and the PCT is a priority.

Family physicians use screening tools to identify palliative patients (Would you be surprised if this patient died within the next 12 months? -the surprise question) and then refer such patients to the PCT. Care plans are developed and implemented as a group after an in-depth assessment. Assessment of the palliative patient in the 8 domains of care is critical, particularly from a psychiatric perspective. It is estimated that about 25-30% of palliative patients suffer from a psychiatric disorder: depression, anxiety, agitation and delirium are some examples. Pharmacologic treatment is different in the care of the dying since there may not be time for the standard treatments, like SSRIs for depression, to work. Psychiatrists working in oncology or palliative care use faster methods to relieve symptoms. The 8 domains of care are:

- Disease management: care coordination
- Physical issues: symptoms
- Psychological issues: emotions
- Social issues: financial, Power of Attorney for Personal Care
- Spiritual: values and beliefs
- Functional: Activities of Daily Living
- EOL treatment plan/goals of care
- Loss/grief

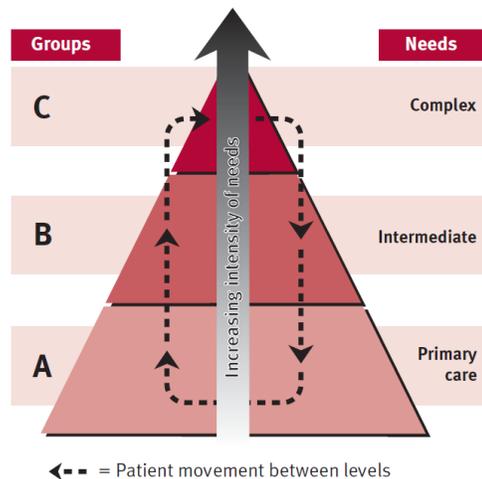
The involvement of the PCT is flexible and is dictated by the needs of the patients, the families and the family physicians. The advance practice nurse, in particular, is the key point of contact among the family physicians, patients, families and other PCT members.

Research studies support the use of innovative expert-consult teams. A recent studyⁱ of these teams in 11 regions of Ontario between 2009-2011 found that the use of expert-consult teams reduced late-life hospital admissions by 30%, the risk of an ED visit by 30%. The number of palliative care patients dying in hospital was reduced by half, The implications for Ontario from this study were summarized by the principal investigator:

- There was previously no evidence using Ontario data showing efficacy of expert-consult teams until this study;
- Now there is compelling evidence that no one-size-fits-all; A cookie cutter approach is not the approach to take in delivery of palliative care in Ontario;
- And local variations in team models based on local resources seem to work;
- Want more people to have access to these expert-consult teams
- Study supports continuing and funding current teams (financially, manpower)

ⁱ Seow H April 2013

- increase capacity of current teams to serve more people;
- New teams in other areas should be developed;
- New variations based on local resources should be encouraged so every Ontarian can have a good death



The figure above shows the optimal delivery of services across care settings. The bulk of palliative care is provided by primary care physicians supported by an expert-consult team when needed. The patient may have complex problems, for example, with pain control and be referred to the tertiary level in-patient palliative care unit, but once recovered steps down to follow-up by a palliative care team in the community and then may be able to continue care with the primary care physician. An ideal, integrated, coordinated regional system can and does let patients move seamlessly across levels of care.

The heterogeneity of the patient population, system structures and other local contextual features, such as geographic diversity or rurality continue to challenge delivery of palliative care in Ontario. A 2010 study^j into the delivery of palliative care in 4 regions, representing both urban and rural settings found significant differences in resource and organization features within the factors of access, capacity and coordination in the provision of quality care. Two regions (one urban, one rural) were found to have a more developed palliative care system than the others with less utilization of acute care resources and a greater number of home deaths. The study identified six key features present in regions with better population-level performance (higher home death rate and lower ED use). These were:

- palliative care specific planning and coordination;
- specified resources, including an advanced practice nursing presence;

^j Sussman j, Barbera l et al. Health system characteristics of quality care delivery: a comparative case study examination of palliative care in four regions in Ontario. *Pall Med*. Published online Aug. 10, 2011. Accessed Jan. 16, 2014

- 24/7 palliative care team access;
- use of a patient common chart to facilitate provider communication;
- standardized patient assessments;
- designated roles for the provision of palliative care services.

This study provides further support for a coordinated team-based shared-care approach to the delivery of palliative care in the community, but also demonstrates the need for careful planning and coordination in implementation. Part of the reason for the fragmentation in some LHINs may be due to lack of clarity around the role of the CCACs who were funded in 2005 to provide palliative care and the role of the LHINs in the provision of community-based, integrated palliative care. Ideally, community-based care would be integrated with out-patient and in-patient palliative units and hospices.

When Death is Imminent

Communication is critical in all aspects of end-of-life-care from advanced care planning, through normalizing death to palliative care. Patients identified clear, honest communication with their doctor as one of their top priorities in EOLC. Honest communication is vital when death is fast approaching. A treatment plan must be developed reflecting the patient's wishes and values so they can have the type of death they choose and avoid unwanted, invasive interventions. Ideally, the physician drawing up the goals of care plan is the treating provider and known to the patient and family, but it could be the intensivist in the ICU where the patient was brought in crisis. There may be a need for a new fee code to compensate the intensivist who has the goals of care discussion with the dying patient and/or his/her family members. Even when the patient has engaged in advance care planning there will still be a need to have the goals of care discussion since one cannot anticipate all circumstances and choices that have to be made at end of life. Informed consent to goals of care treatment plan for the terminal phase is required from the patient, if capable, or the SDM if the patient cannot speak for him/her self. Physicians need to be supported to undertake this work effectively.

Six common themes predominate the definition of a good death by patients and physicians: symptom management; clear decision-making; preparation for death; completion, contributing to others; and affirmation of the whole person, particularly the psychosocial aspects

There are times when physicians cannot provide all of the services and support that are needed for dying patients. The best end-of-life care occurs when there is a team of providers caring for the patient. One way to obtain this multi-disciplinary support is through hospice. One of the few randomized control trials of hospice^k showed that, compared with usual care, hospice increased patient satisfaction and decreased family anxiety.

There are 35 operating hospices in Ontario with a total of 251 open beds. The MOHLTC funds 26 residential hospices for nursing and PSW care while the LHINs fund an additional four hospices and five receive no government funding. Eight hospices are in the planning stage currently. Hospices are not distributed evenly across the 14 LHINs. One LHIN has four hospices while

^k Kane RL et al. A randomized trial of hospice care. *Lancet* 1984;1:890-894

several LHINs have none. A factor in the location and distribution of hospices is private fundraising which pays for the capital and some operating costs for hospices. Seen through an equity lens, this means higher socio-economic areas have better access to hospice care.

Provincial Steering Committee

A Provincial Steering Committee has been struck to advance palliative care in Ontario. The Provincial Steering Committee, chaired by Erie-St. Clair LHIN CEO, Gary Switzer and Bill McLeod, CEO, Halton LHIN, was formed to implement the recommendations from the 2011 document titled *Advancing High Quality, High Value Palliative Care In Ontario: Declaration of Partnerships and Commitment To Action*. The steering committee has identified five priorities:

1. Early identification and access to services and supports
2. Strengthen palliative policy guidance and direction
3. Create effective planning and measurement tools to ensure resources are used optimally, based on need
4. Establish consistent and standardized education and competency requirements for all levels of care provision across care settings
5. Broaden physician engagement

Summary

There is extensive work already being done in palliative care. The OMA wants to ensure that the work is integrated with activity occurring elsewhere in the system to support advance care planning. The OMA's End-of-Life Care Strategy provides a framework to bring a wide range of health care providers, non-health care professionals and the public together to improve the quality of dying in Ontario.