

Palliative care: Therapy for the living

Studies have confirmed that suffering can be relieved and patients can live well until they die when palliative care is introduced early and integrated into the management of serious illness.

ABSTRACT: Palliative care arose as a movement from outside academic medicine in the middle of last century as a response to “bad dying.” Today, palliative care improves quality of life, patient and family satisfaction, length of hospital stay, and health care costs near the end of life. Newer studies have demonstrated a survival advantage when palliative care is introduced early in the illness trajectory. In BC, physicians wishing to acquire more palliative care knowledge and skills can use practice supports provided by the General Practice Services Committee, including a useful algorithm and other clinical tools. In future, the integration of palliative care into the management of all serious illness and greater involvement of the wider community can be expected to help more patients live their remaining life to the fullest and experience a natural, comfortable death.

In the middle of last century, British psychiatrist John Hinton documented the medical deficiencies in end-of-life care: “We emerge deserving of little credit, we who are capable of ignoring the conditions which make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced.”¹ At the time he wrote this, patients were treated until they died uncomfortably in hospital, surrounded by machines, rather than in a place of comfort, surrounded by family and friends. Shared decision making was unheard of. Palliative care arose from a movement outside of medicine as a response to what was recognized by some as “bad dying.”

Both medicine and palliative care have changed much since then. We live longer and age with less disability than ever before. Our system is well designed to treat and modify acute diseases that used to result in death. But medicine’s ability to rescue people from the cliff of sudden fatal illness has led to the accumulation of morbidities and a longer period of disability and dying. Perhaps the most challenging clinical skill these days is finding a balance between prolonging living and prolonging dying.

Palliative care is no longer try-

ing to gain acceptance as a medical discipline—experience and research have now established palliative care as an evidenced-based field of medicine with a defined set of principles, body of knowledge, and skill set. Palliative care has expanded from serving patients with cancer to serving those with any life-limiting diagnosis, including multimorbidity and frailty. Much more than passive care is needed to ensure a comfortable death, and today palliative care strives to help patients live well until they die. What living well entails is unique to each patient and family.

Helping patients with terminal illness live their remaining life to the fullest by communicating well and balancing interventions to achieve a natural, comfortable death requires that all physicians embrace essen-

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tial palliative care knowledge and skills. Expecting physicians to diagnose, initiate, and maintain treatments without knowing how to deliver palliative care is akin to expecting a pilot to take off and transport passengers safely without knowing how to land the plane. Having essential palliative skills and being aware of what specialized palliative care can do for people with advanced illness is the standard of care today.

Definition of palliative care

Palliative care supports patients, their loved ones, and treating clinicians by addressing physical, social, psychological, and spiritual suffering. This is done using advanced communication techniques to establish goals of care and then matching treatments to these individualized goals and providing sophisticated care coordination.² Palliative care is no longer reserved for a time when all disease-modifying therapies have failed, and can be introduced early in the illness trajectory to prevent psychological and spiritual suffering through multidisciplinary care. An early definition states that palliative care “affirms life and regards dying as a normal process” and that it “intends neither to hasten or postpone death” (World Health Organization, 1990, www.who.int/cancer/palliative/definition/en/). Current definitions continue this theme of respecting the process of natural dying. Although involved in dying, palliative care aims to help people live as fully as possible until natural death. There are many myths about palliative care (see **Table**)³⁻¹¹ and one of the newest is that physician-assisted death is an extension of palliative care. Physician-assisted death is not in keeping with palliative care principles, and there is a realistic concern that patients who are already reluctant to self-identify as requiring palliative

care may become even more reluctant if the range of services is perceived to include physician-assisted death.

Outcomes of palliative care

Palliative care services (inpatient, outpatient, and community) have repeatedly been found to improve patient and family satisfaction with care, to improve symptom control and quality of life, and to reduce health care utilization in the last months of life.^{1,12,13} These benefits are seen in patients with cancer, neurological disease, multimorbidity and frailty, and organ failure.

Research in acute care shows that earlier referral leads to a greater positive impact on length of stay and health care costs.¹⁴ Research has also revealed that patients and families received significantly less benefit when they felt they had been referred “too late.”¹⁵ Late implementation of palliative care can result from poor communication, health care provider lack of awareness of palliative care therapies, physician reluctance to discuss end-of-life issues due to prognostic uncertainty, and patient or family reluctance to consider palliation due to persistent myths about palliative care.

Table. Palliative care myths and realities.

Myth	Reality
Opioids shorten life.	There is no evidence that opioids shorten life when dosed appropriately and titrated to control symptoms. In fact, multiple large studies have shown no relationship between opioid dose or dose escalation and time to death. Also, research confirms that appropriate doses of opioids do not cause respiratory depression in patients with dyspnea due to advanced disease.
Patients with a history of addiction should not be prescribed opioids in the palliative care setting.	Physicians have a moral obligation to treat pain in all patients, including those with addiction. Opioids are often necessary and should not be withheld, even though management may be more complex and involve closer monitoring, interdisciplinary involvement, and tighter control of drug dispensing.
Palliative care is only for patients who are at the end of life and have not responded to disease-modifying therapy.	It is appropriate to pursue a palliative approach to care whenever disease or its treatment begins to have a significant impact on quality of life, quantity of life, or both. Physicians with palliative care skills can help patients from the time an incurable illness is diagnosed (e.g., by communicating to increase prognostic awareness) and continuing through the illness trajectory (e.g., by discussing advance care planning).
Palliative care should be provided only when patients meet the criteria for palliative care billing incentives or qualify for the BC Palliative Care Benefits program (< 6 months prognosis).	Palliative care skills and knowledge can benefit patients early in the illness trajectory, as described above.
Choosing palliative care means giving up hope.	Even when hope for a cure is no longer possible, palliative care allows patients to hope to live as well as they can and for as long as they can.
When symptoms are difficult to manage, sedation until end of life is the only option.	Specialist palliative care opinion should be sought in this situation. Experts are available in all health authorities and can be contacted by physicians located outside major centres. Also, physicians can call the toll-free BC Physician Palliative Care Consultation Line.

The integration of palliative care into chronic disease management and oncology care has been recommended now for over 10 years,¹⁶ but referrals are still coming far too late for this model to be considered effective. Advocacy for earlier referral has led to related streams of research designed to answer two important questions: What is the best model for providing palliative care in chronic illness? Does early palliative care have benefits beyond relief of symptoms?

Benefits of early palliative care

In the last 10 years there have been a number of high-quality randomized controlled trials (RCTs) of early palliative care versus usual care in the study of outcomes such as symptoms, mood, quality of life, and survival. The best known RCT is a study of 151 patients newly diagnosed with metastatic lung cancer.¹⁷ Patients were randomly assigned to receive either usual oncology care or early palliative care integrated with oncology care. Quality of life, mood, and survival were tracked. Patients receiving early palliative care had significantly better quality-of-life and mood scores. They also survived 2.7 months longer than those who received usual care, despite undergoing fewer chemotherapy treatments than their counterparts receiving usual care. A qualitative analysis of the difference in the character of the visits is revealing.¹⁸ Patients who received usual oncology care discussed symptoms, the state of their cancer, as well as potential chemotherapy treatment and complications. Patients who received palliative care discussed symptoms and their management as well, but they also had the opportunity to increase their prognostic awareness and strengthen their coping skills during palliative care clinic visits. Because

of this study and other similar RCTs, the American Society of Oncology released a provisional clinical opinion in 2012 recommending combined palliative care with oncologic care for any patient with metastatic disease or high symptom burden.¹⁹ This recommendation has yet to be implemented in Canada.

A further systematic review of 28 randomized clinical trials of early palliative care integrated with usual chronic disease management found benefits to the early inclusion of palliative care,²⁰ but there are serious methodological differences between all these studies and further research is needed to answer two key questions: When is the optimal time to integrate palliative care into chronic disease management? What is the best model for the provision of this care?²⁰ There are many challenges involved in end-of-life care research, but there will eventually be evidence to support a model that allows us to care for patients and families seamlessly from diagnosis through to death and bereavement, helping patients deal with the impact of the disease on function and quality of life, and supporting survivors.

Incorporating palliative care into your practice

Research is improving our understanding of symptom management and the prevention and relief of suffering, but the challenge lies in applying this new knowledge and changing the care provided to patients. Essential competencies in palliative care are being incorporated into Canadian education programs at both the Royal College of Physicians and Surgeons and the College of Family Physicians. The competencies include basic management of pain and other physical symptoms, management of anxiety and depression, and specific communi-

cation skills. All physicians must be skilled in discussing prognosis, CPR status, goals of care, and suffering.²¹ The symptom management and communication competencies apply for all physicians who provide serious illness care: primary care physicians, general and subspecialty internists, general and subspecialty surgeons, and pediatric physicians and surgeons.

Many patients receive end-of-life care through their family physician in collaboration with community or hospital nursing services. Knowing from study results that early palliative care can improve quality and quantity of life, it is important for family physicians to continue incorporating these new skills and knowledge into their practice.

Doctors of BC through the General Practice Services Committee has developed a number of learning modules to improve care for patients with chronic conditions (see **Box** describing palliative care resources for both health care providers and patients). One of these, the End-of-Life module, can help physicians identify patients who could benefit from a palliative approach to care, increase physician confidence and communication skills, and improve collaboration with specialist services, patients, families, and caregivers. The module encourages physicians to keep a database of patients requiring a palliative approach to care to ensure timely discussion of advance care planning and recommends seeing patients regularly to maintain optimum symptom control and prevent suffering. A number of physicians have found the resources in the End-of-Life module useful for building palliative care processes into the care of their patients with chronic illness (www.gpscbc.ca/content/end-of-life-module-helps-family-doctors-discuss-planning-death-patients).

The module includes an excel-

lent algorithm with links to symptom management guidelines, communication tips, and the necessary forms to ensure that patients receive all the benefits and resources they are entitled to. Keeping this active document on the office computer gives the physician access to end-of-life tools for use throughout the illness trajectory.

In BC, all patients who are estimated to be in the final 6 months of life are entitled to support under the Palliative Care Benefits program (www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/pharmacare/prescribers/plan-p-bc-palliative-care-benefits-program), which provides free access to symptom management prescriptions and over-the-counter medications for constipation and other concerns. This same program allows health authorities to provide equipment in the home when appropriate. While such benefits support patients in the 6 months

immediately prior to death, the use of palliative skills and knowledge can start much earlier in the illness trajectory.

When to introduce palliative care

In past centuries when no disease-modifying therapy was available, the doctor would spend time discussing prognosis after making the diagnosis. Being able to predict the course of the illness and its eventual outcome was dependent on knowing the disease and its natural history and likely complications, and knowing the patient with the disease. A good physician was a good judge of prognosis. Because we now have multiple therapies to offer patients diagnosed with life-limiting disease, we often skip over the fact that organ failure, neurodegenerative disease, and cancer will eventually lead to death. However, prognosis has always been important for the patient and family, and even early in the ill-

ness trajectory there is an opportunity to speak in general terms about the disease and the involvement of palliative care at some point along the way. Palliative care can be characterized as “a way to add an extra layer of support and to allow you to live as well as you can for as long as you can.” It is also a way to raise the topic of advance care planning and help patients understand some of the decisions they may need to make down the road and identify people they wish to involve in this process. Patients have repeatedly said they expect physicians to initiate this conversation as part of their care.²²

Estimating prognosis is a devil we all wrestle with. Prognostic estimation tools are inherently faulty because they only consider physical symptoms, signs, and disease indices and cannot factor in the desire to live to see a grandchild born or readiness to “let go.” Nevertheless, patients who are aware of their prognosis

Box. Palliative care resources

Resources for care providers

General Practice Services Committee (GPSC)

End-of-Life Tools and Resources:

www.gpsc.bc.ca/what-we-do/professional-development/psp/modules/end-of-life/tools-resources

Source for useful forms (e.g., Application for Death Certificate, No CPR form), assessment tools (e.g., Palliative Performance Scale, Edmonton Symptom Assessment System), clinical tools (e.g., Joint Protocol for Expected/Planned Home Deaths in BC, Fraser Health's Hospice Palliative Care Symptom Guidelines), and an algorithm (www.gpsc.bc.ca/sites/default/files/Algorithm_v7%206%20Mar%202015.pdf) that contains links to many of these resources.

BC Physician Palliative Care Consultation Line: 1 877 711-5757

Provides toll-free 24/7 access to a palliative care physician able to offer symptom management information and other advice.

iPal: www.ipalapp.com

Free website-based app that works on all mobile devices and desktops to provide essential information about assessing need for palliative care, managing symptoms, and communicating.

Canadian Virtual Hospice: www.virtualhospice.ca

Source for articles, videos, and online courses on palliative care for health care providers.

Resources for patients and families

Compassionate Care Benefits:

www.esdc.gc.ca/en/ei/compassionate/index.page

Source of information about benefits available to eligible individuals who must be away from work temporarily to provide care or support to a family member who is seriously ill and at risk of dying.

Speak Up: www.advancecareplanning.ca

Source of information about advance care planning and end-of-life care, as well as about issues related to an aging population and a strained health care system.

Canadian Hospice Palliative Care Association:

www.chpca.net

Provides access to an excellent handbook for caregivers (www.chpca.net/family-caregivers.aspx) and other information about achieving quality hospice palliative care for all Canadians and increasing awareness of end-of-life care issues in Canada.

Canadian Virtual Hospice: www.virtualhospice.ca

Best overall website for patients and families looking for information about palliative care, end-of-life care, and grief.

and its inherent uncertainty are able to participate more fully in decision making about further investigations and therapy. Informed consent is only truly informed when this issue has been discussed openly.

A palliative approach is certain to be of benefit to patients who are in their final 6 months of life, and criteria to aid in identifying these patients have been developed. Providence Health Care has adapted criteria from a consensus report about how to identify those in need of a palliative care assessment in a hospital setting.²³ The method begins with the validated question “Would you be surprised if this patient died in the next 6 to 12 months?”²⁴ General criteria for serious illness and disease-specific criteria from the literature are combined to identify patients likely to have a prognosis of 6 months or less. While there is no way to calculate how multiple diseases change the prognosis, it is known from several large studies of multimorbidity that the number of medical conditions can accelerate progress through the illness trajectory, likely indirectly through the effect of increasing disability, which has a direct adverse effect on mortality.²⁵

When to consider specialist palliative care

When to refer a patient to a palliative care specialty team depends on the knowledge and skills of the primary care physician and a number of other factors. If the primary care physician has up-to-date palliative care knowledge and skills, specialist palliative care may not be needed. Specialist palliative care can be helpful when:

- Physical and psychological symptoms and spiritual distress are not responding to the usual therapies.
- The patient or family members or health care providers are uncertain about or disagree over goals of care.

- The patient or family members are distressed despite explanations.

A team approach to care is always better for the patient and family because it is near-impossible for one person, the physician, to meet the complex needs of a patient and family struggling with a life-limiting illness. Having access to a team depends on the size and resources of the local area. In a smaller community, the team may consist of the family physician, home care nurse, pharmacist, and neighbors. Other centres may have local hospice societies or physicians with added training in palliative care. Tertiary palliative care programs are only found in large cities, but should always be considered a resource for smaller communities.

Specialist (nonpalliative) physicians also should ensure they have essential symptom management skills as well as the ability to communicate about diagnosis, prognosis, and advance care planning. Specialists can assist the primary care physician in providing appropriate care for the patient by estimating prognosis or indicating the patient’s place in the trajectory of the illness. For example, if a patient with COPD and shortness of breath at rest visits the respirologist and is deemed to be on maximal therapies (home oxygen and medications), the respirologist may indicate that the patient has advanced disease and at this stage would benefit from small doses of opioids to manage dyspnea. Informing the patient of this supports a shared-care approach and allows the primary care physician to provide the needed symptom management and communicate further about planning because now everyone is aware of the prognosis.

All the health authorities in British Columbia have palliative care programs with experts who can be contacted by physicians working outside

the large centres. In addition, physicians in British Columbia and Yukon have access to a toll-free phone line for palliative care consultations. This line connects the physician with a palliative care physician in Vancouver who can advise on symptom management and other issues. This service is billable for the calling physician who is seeking assistance.

The future of palliative care

Despite decades of effort to make palliative care an integral part of medical care, there is ample evidence that people are still dying without access to adequate symptom management and while receiving care that does not reflect their preferences.^{26,27}

A public health approach to palliative care may be the way to reorient care in advanced serious illness and move forward. This approach acknowledges that serious illness involves the whole community and that a few specialized health care providers cannot meet all the needs of a patient and family affected by serious illness. It is everyone’s obligation to influence and contribute to the system of care for someone with advanced illness. The underlying principles for approaching care in this way are from the Ottawa Charter for Health Promotion (World Health Organization, 1986, www.who.int/healthpromotion/conferences/previous/ottawa/en/index1.html), which affirms the need to:

- Build public policies that support health.
- Create supportive environments.
- Strengthen community action.
- Develop personal skills.
- Reorient health services.

A public health approach attempts to involve the whole community in care of patients with serious illness. It looks to establish health and social policy that contribute to identifying and supporting those affected by seri-

ous illness, death, and bereavement. A number of cities in Australia, Ireland, and England have mobilized under the name Public Health Palliative Care International: Developing Compassionate Communities (www.phpci.info) to engage people from various sectors to develop public policy, community action groups, and volunteers to support people living with advanced illness.

Now that the Supreme Court of Canada has overturned the prohibition against physician-assisted death, all physicians will be faced with requests from people fearful of suffering who know they now have an alternative. As other jurisdictions have shown, the vast majority of people wish to die a natural death after living as well as and for as long as they can. Palliative care, delivered as an integrated therapy by skilled practitioners, can help prevent and relieve suffering for most people.

Physicians: Please be motivated to learn about palliative care—for your patients, for your loved ones, and for yourself.

Competing interests

None declared.

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