

1. PALLIATIVE CARE IS AN INCREASINGLY IMPORTANT PUBLIC HEALTH ISSUE

A. Palliative care overview

As outlined in the 2011 report by the Parliament of Canada, Canadians have the right to compassionate end-of-life care that addresses their needs in line with their preferences, and to dignified death free from suffering.¹⁸ Individuals with life-limiting illness suffer from a range of other issues that are linked to their health conditions or social circumstances such as loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide.¹⁹ These can lead to further debilitating health problems. What complicates the end-of-life issue is that the affected patients are not the only ones who suffer and need support. Caring for a dying family member places immense emotional, financial, and social stresses on the whole family.²⁰ The profound needs of the terminally ill and dying persons and their caregivers necessitate quality palliative care.²¹

Palliative care is an approach to care that aims to achieve the best quality of life for the terminally ill, persons who face a debilitating chronic condition, and their families according to the individual's goals of care. Palliative care strives to:²²

- minimize suffering
- treat all active issues
- prevent new issues from occurring
- address person's physical, psychological, social, and spiritual issues, and their associated needs, hopes and fears
- promote opportunities for meaningful and valuable experiences, and personal and spiritual growth
- prepare for and manage end-of-life choices
- help families and survivors cope with the challenges of providing care, as well as with loss and grief

Figure 1 illustrates how hospice palliative care plays a significant role in patient's experience through the illness trajectory, not only at the end-of-life. Treatments of the disease decrease as illness progresses, while palliative care increases as the person reaches the end-of-life. Palliative

¹⁸ PARLIAMENT OF CANADA. QUALITY END-OF-LIFE CARE: THE RIGHT OF EVERY CANADIAN. 2011 <http://pcpsc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

¹⁹ Kellehear A and Abel J. Compassionate Cities Charter. <http://www.phpci.info/#!/resources/c52k>. Accessed April, 1, 2015

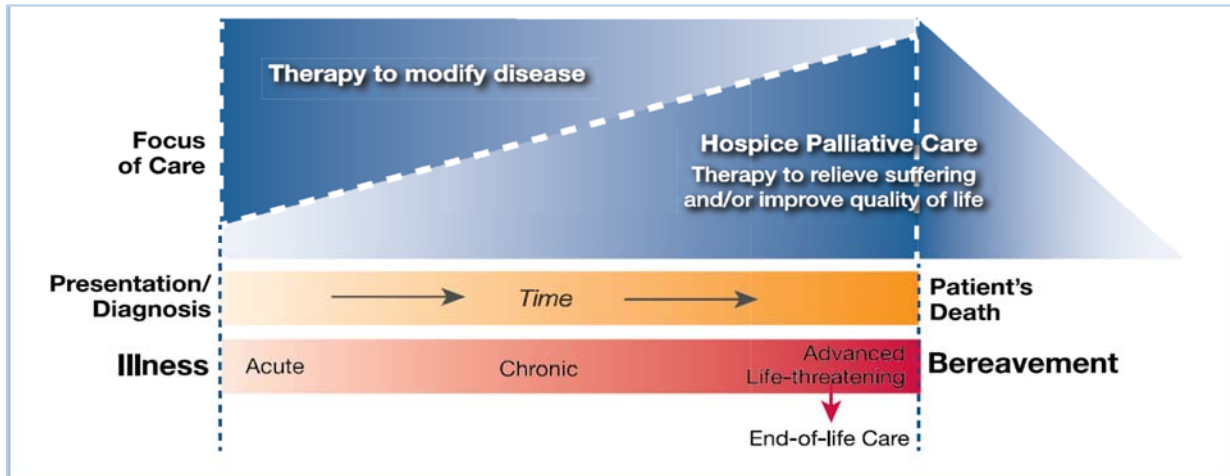
²⁰ Mangan PA, Taylor KL, Yabroff R, Fleming DA, Ingham JM: Caregiving near the end-of-life: Unmet needs and potential solutions. *Palliative and Supportive Care* 2003, 1(3):247-259

²¹ Kaasa S, Radbruch L. Palliative care research – priorities and the way forward. *European Journal of Cancer*, 2008, 44:1175–1179.

²² Health Canada: Canadian Strategy on Palliative and End-of-life Care: Final Report. [http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2007-soin_fin-end_life/index-eng.php] Accessed on March 25, 2015

care also provides support for the family during this entire period. After the patient dies, it is important to provide bereavement counselling for family and friends.

Figure 1 Spectrum of Palliative Care Services



Source: Canadian Hospice Palliative Care Association – A model to guide hospice palliative care 2013

B. Guiding principles to palliative care:

The Canadian Hospice and Palliative Care Association has set well-defined principles to guide programs towards good quality hospice palliative care.²³ These principles are:

- **Person/Family Centred**

When palliative care is provided, the ill person and his/her family are treated as a unit. The person is engaged in all aspects of care which are provided in a manner that is sensitive to the person’s and family’s personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process. There is a valuable distinction to be made between patient-centred and person-centred, with the former being focused on the illness role and the latter focussing on the whole person for whom illness is but one part of life.

- **Ethical**

All hospice palliative care activities are guided by the ethical principles of autonomy, beneficence, non-maleficence, justice, truth-telling and confidentiality. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

²³ CHPCA: A model to guide hospice and palliative care. 2013 <http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf>. Accessed March 25, 2016.

- **Accessible**

All individuals and families have equal access to hospice palliative care services when they need it and where they need it: at hospitals, long-term care facilities, hospices, and the home.

- **High Quality**

All hospice palliative care activities are guided by standards of practice based on nationally accepted principles and norms of practice, and standards of professional conduct for each discipline.

- **Safe and Effective**

All hospice palliative care activities are conducted in a manner that ensures confidentiality, privacy, safety and security. Care that is beneficial and does not create undue risk or burden. Care without any form of coercion, discrimination, harassment or prejudice.

- **Team-Based/Circle of Care**

Hospice palliative care is most effectively delivered by an inter-professional team of health care providers who are both knowledgeable and skilled in all aspects of care within their discipline of practice. The professional team works with family members, friends and other caregivers to form a circle of care around the person and family. Palliative care teams typically include physicians, nurses, allied health care professionals (e.g. physiotherapists), social workers, spiritual advisors, bereavement support workers, trained volunteers, and informal caregivers such as family members and friends.

- **Adequately Resourced**

The financial, human, information, physical and community resources are sufficient to support the organization's activities and its plans.

- **Collaborative**

Each community's needs for hospice palliative care are assessed and addressed through collaborative efforts/partnerships among organizations and services in the community.

- **Advocacy-Based**

Regular interaction with legislators, regulators, policy makers, health care funders, other hospice palliative care providers, professional societies and associations, and the public increases awareness of hospice palliative care activities and the resources required to support them.

- **Evidence-Informed and Knowledge-Based.**

The development, dissemination and integration of new knowledge improves the quality of hospice palliative care. All activities are based on the best available evidence. Ongoing

education of all persons, families, caregivers, staff and stakeholders is integral to providing and advancing quality hospice palliative care.

Figure 2 Guiding Principles to Palliative Care Programs



Source: Canadian Hospice Palliative Care Association. A model to guide hospice palliative care 2013

C. Why palliative care became an important public health issue?

More than a decade ago the World Health Organization made a global call for all countries to consider palliative care as a public health problem and include it in their health agendas.²⁴ Since then an increasing number of health systems across the world started to look into the escalating unmet care needs of the frail elderly and terminally ill people, and many concur with the WHO that palliative care is indeed a public health issue.^{25 26}

Like elsewhere in the developed world, end-of-life care provision in Canada is facing extreme challenges due to the rapidly evolving palliative care practice, socio-demographic changes in

²⁴ World Health Organization: Palliative Care www.who.int/cancer/palliative/en/ WHO

²⁵ Higginson IJ., Koffman J.: Public health and palliative care. *Clin Geriatr Med* 2005; 21(1):45–55, viii.

²⁶ Stjernsward J., Foley KM., Ferris FD. The public health strategy for palliative care. *J Pain Symptom Manage* 2007;33(5):486-93

the end-of-life context, and health care system constraints.²⁷ These challenges have led to palliative care being on public and government agendas across Canada as an increasingly important public health issue.²⁸ In 2014, the outcomes of a national dialogue on EOL care revealed strong public support for greater access to palliative care.²⁹ Bill 52 in Quebec passed in June 2014, legalizing medical-aid-in-dying (euthanasia) and promising palliative funding.³⁰ In May 2014, a private members' bill was approved in Parliament calling for a national palliative care strategy.³¹

In 2015, the Quality of Death index which assesses availability, affordability and quality of palliative care available to adults across 80 countries ranked Canada in the 11th place (compared to the 9th place in 2010). In terms of affordability of palliative care and costs to the family, Canada was ranked in the 22nd place behind the United States and United Kingdom. According to the Quality of Death index, the United Kingdom is a leader in palliative care, thanks to extensive integration of palliative care into their National Health Service and strong hospice and community partnerships movement.³²

The following section presents an analytic overview of the palliative care challenges and documented gaps in the provision of health care services across Canada.

Changes in palliative care practice

Palliative care in Canada started off in acute care hospitals and many of the challenges in Canada relate to getting palliative care out to community based settings where those who live with serious illness actually spend most of their last year of life. It has also been seen increasingly as the domain of specialised palliative care teams and so recently the Way Forward Initiative has created a roadmap to ensure integration of a Palliative Approach to C throughout the health care system. Also in Canada defining Palliative Care as a specialty has lagged behind other developed nations and therefore it has primarily been delivered by primary care physicians – some of whom may have had some specialized training. Palliative medicine has now been approved as a sub-speciality (with its first intake in 2017) and there is a growing understanding of the need for an integrated system of care with primary care, secondary levels of care and

²⁷ Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2014

²⁸ Williams et al. Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? BMC Public Health 2011; 11:335

²⁹ <https://cmadialogue.ca/en/>

³⁰ <http://www.assnat.qc.ca/en/travaux-parlementaires/projets-loi/projet-loi-52-40-1.html>

³¹ <http://www.parl.gc.ca/Parliamentarians/en/members/CharlieAngus%2825470%29/Motions?sessionId=151&documentId=6261234>

³² <http://www.lienfoundation.org/sites/default/files/2015%20Quality%20of%20Death%20Report.pdf>;

specialized providers who can not only provide care for complex patients but also do research, educate, coach and mentor all who provide care to seriously ill patients.³³

Today, it is recommended that palliative care is

Provided on the basis of need, not diagnosis or prognosis – Palliative care is no longer limited to illnesses that are deemed terminal. According to modern definitions and models, palliative care should be available to persons with chronic conditions, people who are frail, as well as terminally ill patients.^{34 35 36}

Not restricted to end stage of life – Research has confirmed that palliative care is more beneficial to patients and family caregivers when provided early in the course of illness ideally at time of diagnosis. Multiple studies showed that early palliative care improves symptom management, quality of life and mood among patients with advanced cancer.^{37 38 39 40} In addition to these benefits, two studies based on randomized controlled trials among patients with non-small-cell lung cancer carried out by Temel and colleagues concluded that early integration of palliative care with standard oncologic care may result in prolonged survival, improved patient perception of prognosis, greater documentation of resuscitation preferences in medical records, as well as less aggressive care and resource use at the EOL.^{41 42} Similar benefits were reported for caregivers. A recent randomized controlled trial showed that early palliative care in the form of coaching and bereavement support, significantly lowered depression and stress burden among family caregivers of patients with advanced cancer.⁴³

These benefits demonstrated for both patients and caregivers have led to the development of new models of care such as the Bow tie model, which aims to facilitate earlier acceptance of palliative care in conjunction with disease modification therapies from the time of

³³ <http://www.eapcnet.eu/LinkClick.aspx?fileticket=zdT-uqg5EJo%3D&tabid=38>

³⁴ Van Mechelen et al. Defining the palliative care patient: a systematic review. *Palliative Medicine* 2013; 27(3):197-208. PubMed PMID: 22312010

³⁵ Canadian Hospice Palliative Care Association: A model to guide hospice and palliative care. 2013 <http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf>. Accessed March 25, 2016.

³⁶ World Health Organization (WHO) (2002). WHO definition of palliative care. Available from <http://www.who.int/cancer/palliative/definition/en/>.

³⁷ Zimmermann C, et al. Early Palliative Care for Patients with Advanced Cancer: A Cluster Randomized Controlled Trial. *The Lancet* 2014;383:1721-30

³⁸ 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;302:741-9

³⁹ Dalgaard KM, Bergenholtz H, Nielsen ME, Timm H. Early integration of palliative care in hospitals: a systematic review on methods, barriers, and outcome. *Palliative and Supportive Care* 2014: 1-19.

⁴⁰ Wright, A.A., Zhang, B., Ray, A., et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, 2008; 300: 1665–1673.

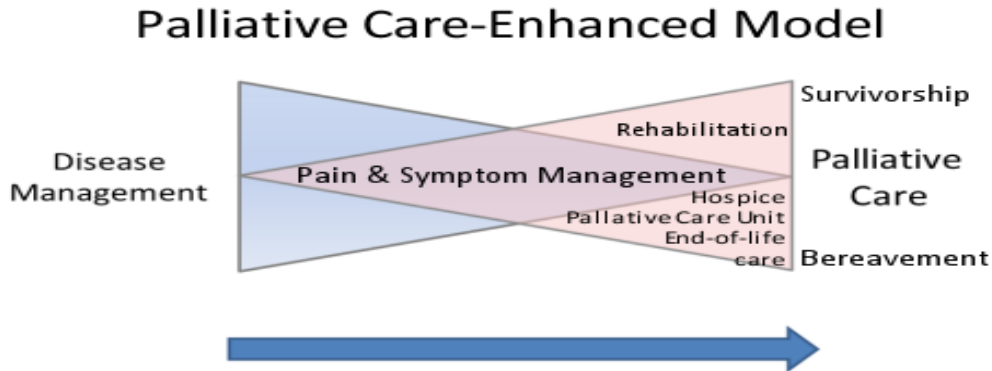
⁴¹ Temel JS, et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. *N Engl J Med* 2010; 363:733-742.

⁴² Temel, J., Greer, J.A., Admane, S., et al. (2011). Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: Results of a randomized study of early palliative care. *Journal of Clinical Oncology*, 17, 2319–2326.

⁴³ Dionne-Odom et al. Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial. *JOURNAL OF CLINICAL ONCOLOGY* 2015; 33 (13): 1446-1452

diagnosis. (See Figure 3)⁴⁴ The Bow tie model serves as a communication tool that helps people see and accept palliative care as an essential part of medical care and thereby maximize the time that people would benefit from the wide variety of palliative care interventions available.

Figure 3 The Bow Tie Model: Early Integration of Palliative Care in Disease Management



Not limited to any one care setting- Palliative care is provided wherever a person’s care takes place, whether this is the patient’s own home, a community care facility, hospice in-patient unit, hospital, or outpatient or day care service.

Multidisciplinary and provided at all levels of care - Care is not limited to specialist palliative care services but is provided at primary and secondary levels of care as well. Services are broad and multidisciplinary to address the patients’ multidimensional needs and this requires integration and alignment of services across different sectors including the health, social, and non-governmental sectors.

Growing demand for palliative care

Health care systems and particularly provision of palliative care are under stress to meet the complex needs of the increasing number of frail individuals, persons who are facing life-threatening illness, the dying and the bereaved. It is estimated that 90% of Canadians who die can benefit from palliative care. However only about 30% of Canadians have access.⁴⁵

⁴⁴ Hawley, Philippa H. **The Bow Tie Model of 21st Century Palliative Care.** Journal of Pain and Symptom Management, Volume 47, Issue 1, e2 - e5. Available at <http://www.jpmsjournal.com/article/S0885-3924%2813%2900609-X/fulltext>.

⁴⁵ Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2012 http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf

- **Population is aging**

Older people frequently have multiple debilitating conditions such as dementia that escalate their palliative care needs dramatically.⁴⁶

In Canada, seniors make up the fastest-growing age group. In 2011, an estimated 5.0 million Canadians were 65 years of age or older, a number that is expected to double by 2036 to reach 10.4 million. The number of Canadians aged 80 years and over is projected to increase as well to nearly 5 million in 2036 compared with 1.4 million in 2013.⁴⁷ The estimated prevalence of dementia is higher among those aged 80 years and older, with a rate of 212 per 1,000. Older seniors represent 55% of Canadians with dementia.⁴⁸

British Columbia will have the oldest population west of Quebec by 2036.⁴⁹ It is projected that the percentage of BC population aged 65 and over will increase from 15.7% in 2011 to reach between 24% and 27% in 2038. As for older seniors, the estimated number of British Columbians who are 80 years of age or older in 2013 (207,000 older seniors) will double by 2036. This trend will continue for the next several decades due mainly to an increase in life expectancy, the aging of the baby boomer generation, and immigration.⁵⁰ With time, this will have dramatic impacts on the need for palliative services and the health system will be under increasing pressure to provide timely, high quality health care to the elderly population.

- **More people suffering and dying from debilitating chronic conditions**

People who have two or more chronic diseases live for months or years in a state of fragile health or “vulnerable frailty”.⁵¹ The frail state of these people often makes their needs too complex and broad to be handled by the current structure and functions of the health system.

In Canada, approximately 40% of the population have at least two chronic conditions and two thirds of all deaths are due to chronic conditions. Each death disrupts and burdens the life of about 5 or more other people physically, mentally, and financially. It seems likely, then, that two-thirds (over 20,000) of BC’s 30,000 annual deaths are the result of chronic illness and impact the lives of approximately 60,000 caregivers and other loved ones. As the population ages, this number will increase exponentially.

⁴⁶ Cicely Saunders Institute. London, <http://cicelysaundersinternational.org/research/palliative-care-elderly/> Accessed April 1, 2015

⁴⁷ <http://www.statcan.gc.ca/daily-quotidien/140917/dq140917a-eng.htm>

⁴⁸ <http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php#c3-3>

⁴⁹ Human Resources & Skills Development Canada. (2012). Canadians in context - Aging population. Ottawa, ON: HRDC. Retrieved from <http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=33>

⁵⁰ <http://www12.statcan.gc.ca/census-recensement/2011/as-sa/fogs-spg/Facts-pr-eng.cfm?Lang=Eng&GK=PR&GC=59>

⁵¹ Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2014 http://www.chpca.net/media/330558/Fact_Sheet_HPC_in_Canada%20Spring%202014%20Final.pdf

Deficiencies in end-of-life care

Inadequate access

Although the current demand for palliative care in Canada is high, the access to and uptake of the available palliative services are unexpectedly low. A report by the Royal Society of Canada Expert Panel in 2011 says that 95 per cent of Canadians would benefit from palliative care and yet, "as many as 70 per cent of Canadians lack access because hospice and palliative care programs are unevenly distributed across Canada."⁵² Poor access has also been attributed to other factors as affirmed by researchers and advocates:

- **Palliative care is unknown/poorly understood in society**
Only about half of Canadians are aware of the hospice palliative care concept and had the lowest awareness of access at home.⁵³
- **Lack of awareness of the available palliative care services**
Many Canadians are unaware of what options exist and what palliative care programs available in the community.⁵⁴ Recent survey showed that only 21% of patients had heard the term advance care planning.⁵⁵
- **Services are not available in all the care settings.**
The availability of high quality care at end-of-life varies widely in different settings.⁵⁶
- **Shortage of palliative care specialists**
By international standards, Canada has fewer doctors specializing in palliative care than some comparable countries. The number of palliative care physicians working either part- or full-time in Canada comprises just 0.28% of all Canadian doctors, compared to 0.52% in the US and 0.38% in Australia.⁵⁷
- **Primary care providers often lack basic palliative care skills and knowledge**
Most primary health care providers are not adequately trained to provide palliative care and therefore lack the knowledge and skills needed to support the patient's

⁵² Schüklenk et al. End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making. *Bioethics*. 2011 Nov; 25(Suppl 1): 1–4.

⁵³ <http://www.hpcintegration.ca/resources/what-canadians-say.aspx>

⁵⁴ Canadian Hospice Palliative Care Association. Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging, 2007. Available at http://www.chpca.net/media/7487/Brief_to_Spec_Sen_Comm_on_Aging-HPC_in_Canada.pdf

⁵⁵ <http://www.hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf>

⁵⁶ http://www.qelccc.ca/media/3743/blueprint_for_action_2010_to_2020_april_2010.pdf

⁵⁷ Wanniarachige, D. More palliative care specialists is not enough. *CMAJ News* Jan 12, 2015
<http://www.cmaj.ca/content/early/2015/01/12/cmaj.109-4972.full.pdf>

complex care needs.^{58 59} A recent survey by the CHPCA, through The Way Forward initiative, showed that most family physicians and nurses across Canada are seeking support, education, and resources to increase their capacity in providing palliative and end-of-life care to their patients.⁶⁰

- Over 80% of GP/FPs and nurses want education to help them with the most challenging aspects of managing palliative care patients including pain management, addressing depression, and supporting their patient's emotional needs
 - 68% of GP/FPs and 77% of nurses would like access to palliative care nurses to provide support in the community
 - Over 60% of GP/FPs and nurses would like around the clock access to a palliative care physician for telephone advice
- **Funding is inadequate and cost is often cumbersome to families**
Residential hospice palliative care programs are few and far between and have often been at least 50% funded by charitable donations. Canadian families frequently shoulder at least 25% of total cost of palliative care due to home based services.⁶¹

Inequitable access

Significant inequity is observed between urban, rural, remote, and First Nation communities, as well as culturally and linguistically diverse and vulnerable populations.⁶² Access to palliative care is often described as a situation of privilege rather than a universal entitlement for Canadians.⁶³

Poor quality of care

People who receive palliative care suffer uneven provision of services and disruptive, ineffective care. The following documented deficiencies in the current care provision have contributed to this:

- **Care is not person/family-centred**
Patients are often not informed of their care options and many are not engaged in

⁵⁸ <http://www.cmaj.ca/content/early/2015/01/12/cmaj.109-4972.full.pdf>

⁵⁹ Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2013

⁶⁰ Canadian Hospice Palliative Care Association, The Way Forward Survey: General/Family Practitioners and Nurses in Primary Care, for The Way Forward initiative, Ipsos Reid: 2014. - See more at: <http://www.hpcintegration.ca/resources/health-care-professional-research/primary-care-research.aspx#sthash.IVTj2d0G.dpuf>

⁶¹ Canadian Hospice Palliative Care Association (CHPCA). Fact Sheet—Hospice Palliative Care in Canada. 2014 http://www.chpca.net/media/330558/Fact_Sheet_HPC_in_Canada%20Spring%202014%20Final.pdf

⁶² http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf

⁶³ Williams et al. Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? BMC Public Health 2011; 11:335

planning for their own end-of-life.⁶⁴ Most patients do not receive end-of-life care in their place of choice: research tells us that 70% of Canadians receive most of the end-of-life care in hospitals while most Canadians prefer a home-like setting.^{65 66} In BC, 50-60% of deaths occur in acute care, with a gap in capacity for home death.⁶⁷ A recent study showed that, agreement between patients' expressed preferences for end-of-life and documentation in the medical record was only 30.2%.⁶⁸ Moreover, the emotional and spiritual needs of the persons and the bereaved are frequently not adequately addressed or overlooked. Palliative care teams often lack professionals who can provide psychological, spiritual, and bereavement support. Besides, only a few programs offer culturally and linguistically appropriate care.

- **No standardised approach to care**

National standards for quality end-of-life care in all care settings do not exist. In 2013, the CHPCA published guiding principles and norms of palliative care practice. Complying with these norms is voluntary.⁶⁹

- **Continuity of care is poor**

Canadian patients and family members often experience difficult transitions between providers and settings due to poor information sharing. Barriers include limited staff time, patient privacy regulations and lack of a clear structure and common information system to guide and support sharing of patient information.⁷⁰

- **Inadequate system integration**

The complexity and wide range of needs of older people, dying persons, and caregivers requires joint working between many sectors and between all levels of the health system. Essential elements for system integration are lacking, such as common clinical best practices, tools and processes across sectors; and shared functional and clinical infrastructures.

⁶⁴ CHPCA Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging, 2007. Available at http://www.chpca.net/media/7487/Brief_to_Spec_Sen_Comm_on_Aging-HPC_in_Canada.pdf

⁶⁵ http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_march_2013_final.pdf

⁶⁶ Canadian Institute for Health Information. Health Care in Canada, 2011: A focus on seniors and aging. (Ottawa: CIHI, 2007).

⁶⁷ Institute for Health System Transformation and Sustainability. Shaping Priorities of the BC Centre for Palliative Care Report on an Invitational Consultation. (Vancouver: IHSTS, 2014)

⁶⁸ Heyland DK, Barwich D, Pichora D, Dodek P, Lamontagne F, You JJ, Tayler C, Porterfield P, Sinuff T, Simon J; ACCEPT (Advance Care Planning Evaluation in Elderly Patients) Study Team; Canadian Researchers at the End-of-life Network (CARENET). Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med.* 2013;173(9):778-87

⁶⁹ Canadian Hospice Palliative Care Association. A model to guide hospice palliative care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2013

⁷⁰ https://www.cnaaiic.ca/~media/cna/files/en/cna_cma_heal_provider_summit_transformation_to_integrated_care_e.pdf?la=en

- **System level accountability is not clear**
Accountability frameworks are essential in supporting and advancing the care of patients across sectors, while aligning with operational accountabilities within each sector/service. However, the provision of palliative care lacks a clearly defined system accountability framework that defines the roles, responsibilities and performance expectations of the involved sectors and ensure reporting on system-level outcomes.
- **Lack of performance measures and quality indicators**
Continuous credible assessment, monitoring, and reporting- the main drivers of high quality palliative care- are inadequate at the national level and vary in adequacy and consistency among provinces.⁷¹ National quality indicators do not exist and there are no palliative care registries at the provincial level in BC to assess the quality of the care that palliative patients receive.

Cost of dying is high

Effective palliative care programs have been shown to improve quality of end-of-life while decreasing cost.⁷² Palliative care reduces visits to emergency departments, hospital admissions, length of hospital stay, ICU admissions and, as well, protects the patients from receiving unnecessary diagnostics and interventions.

However, in Canada the current deficiencies in the provision of palliative care resulted in unnecessary use of emergency departments and inpatient hospital care. Furthermore, terminally ill patients who find no appropriate alternative to a prolonged stay in hospital often receive costly aggressive treatment that neither prolong nor improve life.⁷³ As a result, end-of-life care continues to contribute significantly to the escalating cost of the health system. About 20% of health care spending in Canada occurs in the last year of life and the cost of dying for a person with a terminal disease is four times the cost of a sudden death (\$40,000 versus \$10,000 respectively).⁷⁴ In BC 35% of health care expenditures occur in last year of life.⁷⁵ Families, primary EOL caregivers, also experience substantive financial stress in terms of caregiving costs, unpaid leaves, and job loss. It has been estimated that family caregivers provide 75% to

71 Canadian hospice Palliative care Association (CHPCA), Palliative Care in the Community: An Environmental Scan of Frameworks and Indicators, the Way Forward initiative: An Integrated Palliative Approach to care, 2013.

72 Meier De, Beresford I. Palliative care cost research can help other palliative care programs make their case. J Palliat Med. 2009;12(1):15-20

73 Canadian Institute for Health Information. Health Care use at the end-of-life in western Canada (Ottawa: CIHI,2007)

74 Canadian Hospice Palliative care Association (CHPCA) Fact sheet- Hospice Palliative Care in Canada. March 2013

75 http://www.health.gov.bc.ca/library/publications/year/2015_a/primary-and-community-care-policy-paper-exec.pdf

90% of all home care and contribute \$6000 worth of unpaid hours in the last four weeks of life alone.⁷⁶

The provision of palliative care in Canada and in BC in particular is in immense need of a cost-effective approach that can both improve quality of end-of-life care *and* relieve the financial burden on the health care system, on patients, and on families.

⁷⁶ Hollander, M. J., Liu, G., & Chappel, N. L. (2009). Who cares and how much?: The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 42-49