

EXECUTIVE SUMMARY

The BC Centre for Palliative Care (BC CPC) provides leadership to promote excellence in palliative and end of life care for all British Columbians. The Centre was established in 2014 by the Institute for Health System Transformation and Sustainability with funding from the Ministry of Health in support of the BC Provincial End of Life Action Plan. Establishment of the BC CPC represents an important opportunity for greater public engagement to support the development of quality person and family centred care and outcomes for all British Columbians living with and dying from serious or advanced illness. The Centre works collaboratively with health system partners including regional health authorities, care providers, professional bodies and community organizations across BC to promote education around end of life care issues and support evidence-based practice and policy development.

The BC CPC recognizes the social dimensions of living with advanced illness, death, dying, grief and loss and that there is an urgent need in BC to move forward in innovative ways to address both societal concerns and the current issues with the access and quality of palliative care services. This report was commissioned by the BC CPC to provide evidence base for the effectiveness of the public health approach in addressing these concerns and issues.

This report delivers an in-depth understanding of the public health approach principles and elements and describes exemplary public health palliative care (PHPC) models. The experience of Spain, United Kingdom, Australia, Japan, and India with PHPC models are presented in detail in this document. The experience of Germany, Italy, and France, Norway, and Hawaii with the public health palliative care models are described in other publications.^{1 2 3 4 5} The report is based on a review of peer reviewed journal articles, books, reports and websites of governmental and non-governmental organizations and other grey literature. In addition, the report findings are informed by consultations from palliative care leaders and researchers in BC.

The BC CPC intend to use this document to spark and shape discussions about how to advance the PHPC approach in BC through the development of a provincial end-of-life coalition with representatives from clinicians, educators, community agencies, and the public.

¹ Braun KL et al. Kokua Mau: a state-wide effort to improve end-of-life care. *Journal of Palliative Medicine*, 2005, 8:313–323.

² Kaasa S, Jordhøy MS, Haugen DF. Palliative care in Norway: a national public health model. *Journal of Pain and Symptom Management*, 2007, 33:599–604.

³ Radbruch L, Foley K, De Lima L, Prail D, Furst CJ.: The Budapest Commitments: Setting the goals: A joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Help the Hospices. *Palliat Med* 2007:269–271

⁴ <http://www.eapcnet.eu/Home/tabid/38/ctl/Details/ArticleID/1111/mid/878/Default.aspx>

⁵ Schneider N., Lueckmann S.: Developing targets for public health initiatives to improve palliative care. *BMC Public Health* 2010:1–9

Key Findings

The Public Health Palliative Care (PHPC) approach promotes holistic, evidence-based, innovative, community-based, whole systems oriented end-of-life care.

Compassionate Communities – a key feature of PHPC – offer access to the many social aspects of care that are not provided by the health care system (e.g. respite for caregivers, companionship for people with dementia who are often socially isolated, bereavement support for caregivers) but which are central to the well-being of patients with advanced illness and their family / friend caregivers.

There is strong evidence to suggest that the public health approach presents sustainable solutions to the problems of access, equity, and quality of palliative care.

With regards to its impact on patient and system outcomes, the public health approach showed that it:

- improves the person and provider experience
- enhances the quality of life prior to death
- makes it possible for more people to die in dignity in home-like settings
- creates compassionate caring communities
- results in cost savings

The public health approach in the reviewed countries can be described in the form of three models:

1. Whole Systems Model

Example: Catalonia, Spain

A 'Top down/whole systems' model aims to extend health services to community settings through system's efforts. The model focuses on establishing necessary system infrastructure and resources such as: policies, strategy, data/electronic health systems, quality assurance, capacity development, evaluation, and research resources. The 'whole system' model significantly enhanced the quality and value of palliative care delivery in Catalonia.

(See **Figure 10** Catalonia WHO Public Health Palliative Care Project: Results at 10, 15, and 20 Years -Page 48)

Key Message

Over the next 25 years, BC is certain to continue to face system wide challenges in providing timely, cost-effective, person-centred care for seriously ill and frail citizens. As the population increases and ages, the number of British Columbians who will need palliative care is projected to continue rising at a higher pace than the national average.

A public health approach offers a sustainable, whole systems, cost-effective strategy to earlier integration of a palliative approach to care in all settings within the continuum of care and, addressing the system challenges and societal concerns that are negatively impacting the availability and quality of end-of-life care in BC.

2. Health Promoting Model

Example: Kerala, India

A 'Bottom up/health promoting' model recognizes the social character of frailty, illness and dying; emphasizes education and information-sharing; and enhances collaboration and participatory relationships between the health system and the community. In Kerala, the health promoting model involved community-led engagement and development strategies. This resulted in the creation of compassionate communities in which the responsibility of care for experiences of death, dying and loss is shared among province-wide networks of community members and groups. In Kerala, the model successfully expanded the range of palliative care beyond health services and professional care, significantly increased palliative care coverage, and enhanced quality at the end-of-life. (See **Figure 11** Kerala's Experience: Typical activities of NNPC volunteer groups- Page 51)

3. Whole Systems, Health Promoting Model

Examples: United Kingdom, Australia and Japan

A 'Mixed' model recognizes health promotion and awareness as integral parts of a whole system approach to palliative care. This model, which is applied in the UK, Australia and Japan, includes national engagement programs and awareness campaigns, which are often funded and led by the government, to involve the community in planning their own palliative and end-of-life support programs and to prompt and direct society's efforts towards common national objectives. (See Pages 60, 70, 72)

The three PHPC models emphasize the importance of partnerships:

- Partnership between communities, governments, and service providers
- Partnership between care providers: specialists in palliative care, primary care providers, specialists in elderly care and oncology, psychiatrists, and social workers

The implementation of the PHPC models in the examined countries followed a systematic process to integrate incremental transformative changes in existing services and programs, building on existing strengths and making efficient use of the available resources. This process allowed for earlier successes to be achieved and this helped in garnering greater confidence in the PHPC model and sustained support.

Having different models for the public health approach to palliative care indicates that **the approach needs to be tailored to the society's demographic, economic, social, cultural and political factors, taking account the structure and maturity of the health system.**