



A Timeline of Hospice Palliative Care Policy and Practice in Ontario, Canada



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Prologue

List of Acronyms

CCAC- Community Care Access Centre
CCB- Compassionate Care Benefit
CCO- Cancer Care Ontario
HAO- Hospice Association of Ontario
HPC – hospice palliative care

HPCN- hospice palliative care network
MOHLTC- Ministry of Health and Long-Term Care
OPCA- Ontario Palliative Care Association
PCIP- Palliative Care Integration Project

This report examines the evolution of hospice palliative care in Ontario, Canada. As you will notice, several sections will appear in boxes, or within parentheses. Boxes with a tree symbol highlight the hospice palliative care progress specific to rural Ontario, whereas boxes featuring a map of Canada illustrate federal level events. Parentheses encompass italicized text which are direct quotes from key informants who contributed their knowledge of hospice palliative care to this project.

Introduction

Ontario is Canada’s most populated province, having approximately 12 million residents. Most Ontarians, however, live in or around urban areas; the majority of the province’s land area is sparsely populated. Demographically, Ontario represents 40% of the Canadian population [1]. Of that, almost 85% of Ontarians live in urban settings, with 15% living in rural areas as of 2006 [2]. The vast distances and low population density in these areas makes delivering health care services in rural Ontario, including hospice palliative care (HPC), a significant challenge for health policy makers and program planners and providers. Although there are both rural and urban communities in Southern and Northern Ontario, Northern Ontario is predominately comprised of rural communities while Southern Ontario is mostly urban. As depicted in Figure 1, the province of Ontario is divided into fourteen Local Health Integration Networks (LHINs), who are responsible for planning health services in their jurisdiction. As seen in Figure 1 (pg 12), the two LHINs in Northern Ontario serve the largest areas due to low population densities. As a result, much of the progress and program innovation specific to HPC has taken place in the urbanized southern region of Ontario.



The Rural Picture: Rural Canada is home to a high proportion of seniors. Statistics from 2006 show that 33% of the total number of Canadian seniors live in rural areas, accounting for 15% of the population in rural areas; by comparison, seniors only constitute 13% of the population in urban areas [3]. In Ontario, the population of seniors in predominantly rural regions was 16% in 2006, about 1% above the average for Canada [3]. Rural citizens in Ontario advocate that the general lack of health care services, providers, and hospice palliative care (HPC) education and training, in particular, limit the quality and extent of HPC care that is provided to dying people in their home communities. In rural First Nations communities, a lack of resources is complicated by jurisdictional issues between the provincial and federal governments.

Moreover, Ontario is in a unique position, both geographically and politically, because Ottawa, the nation's capital is located within its boundaries. In effect, the evolution of HPC in Ontario has been influenced by the proximity of the capital city as it is the venue for national policy changes.

“Palliative care is active compassionate care of the terminally ill at a time when they are no longer responsive to traditional treatment aimed at cure and prolongation of life and when the control of symptoms, physical and emotional, is paramount. It is multidisciplinary in its approach and encompasses the patient, the family and the community in its scope”
(Ontario Palliative Care Association)

Although the term ‘palliative care’ was coined by Dr. Balfour Mount, in Montreal Quebec in 1976, it was the Palliative Care Foundation, based in Toronto, (now the Ontario Palliative Care Association -OPCA) that defined the term in 1981.

The demand for HPC services in Canada has been exacerbated by an aging population, increased life-expectancies of those with chronic and/or terminal illnesses and the shift of care from hospitals to homes. In 2007, there were 1.7 million senior citizens in Ontario (13.2% of Ontario's population) and population projections show that by 2031 there will be 3.6 million senior citizens (21.9% of the population). The bulk in the projected growth of the senior population is set to take place after 2011 as baby boomers approach their 65th birthdays [4].

To study and track the influence of past policies on the development and progression of current HPC practices, this study was undertaken to examine the evolution of HPC in seven provinces, the latter which were selected based on their representation of Canada's regional diversity (British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec and Prince Edward Island). Interviews were conducted with a number of key informants, which included individuals who were identified as knowledgeable with regard to HPC development in their province. In addition to information provided by key informants, a review of both the academic and grey literature was used to compile a list of key events in order to develop HPC timelines for each province. Despite our efforts, fragmented documentation combined with the need to rely mostly on key informant accounts made the tracking of HPC evolution a difficult endeavor. As a result, it is acknowledged that what has been presented herein has clear limitations. For this reason we encourage readers to share with the research team any information that they feel has been overlooked or misinterpreted (please refer to page 10 for contact information).

This report presents the findings specific to the evolution of HPC in Ontario. As you will note in the table below, the HPC movement began in the late 1970s with most of the foundational groundwork being laid in the 1980s.

“You know the whole policy change[d] in Ontario with the palliative care initiatives to make it easier for people to remain at home if they wished- a societal shift happened...”
(key informant)

Key Provincial Milestones

Below is a list of main events that have helped to shape HPC in Ontario, presented in chronological order. These events were noted by key informants and verified in both the grey and academic literatures. It should be acknowledged that the following list of events is provincially based. Federal initiatives and contributions to these events, although not listed in the table below, will be highlighted in the following section.

Table 1. Chronological Key Provincial HPC Events

1979	First community based hospice opens – The Hospice of Windsor and Essex County
1981	Palliative Care Foundation forms and is based in Toronto; defines ‘palliative care’ (Palliative Care Foundation now the Ontario Palliative Care Association)
1983	First University Institute for HPC research and education forms at the University of Ottawa
1985	Palliative Care Foundation publishes first issue of the Journal of Palliative Care; the issue is dedicated to Dame Cicely Saunders for her instrumental role in the United Kingdom HPC movement
1989	Hospice Association of Ontario (HAO) is founded by nine members
1992	Ministry of Health announces \$4.8 million in funding for four HPC education initiatives including: education initiatives for interdisciplinary providers, education for family physicians, support and maintenance of hospice volunteer visiting programs, and the establishment of regional pain and symptom management teams
1999/2000	Cancer Care Ontario (CCO) and other stakeholders devise the Palliative Care Integration Project (PCIP), an intervention that promoted the use of common tools and guidelines, and implement it in Southeastern Ontario
2004	CCO identifies HPC as a priority area for the first time
2004	Compassionate Care Benefit (CCB) made available to Ontarians
2005	Ministry of Health and Long-Term Care (MOHLTC) announces the End of Life (EoL) Care Strategy pledging \$115.5 million in funding over the following three years to EoL care, including \$4.4 million in funding for nine residential hospices. The purpose of the EoL Care Strategy is to achieve the MOHLTC goals, including integration, coordination and quality of care.
2005	14 Hospice Palliative Care Networks (HPCNs) established for each Local Health Integration Network (LHIN) by MOHLTC
2006	Provincial PCIP program launched, integrating the HPCNs, Regional Cancer Programs and the Community Care Access Centres (CCACs) with support from the MOHLTC and CCO
2006	Family Medical Leave and CCB are amended to make employees eligible to care for extended family members and those who are considered as family
2007	MOHLTC expands funding from nine residential hospices to 15 organizations
2008	The EoL Care Strategy ends.
2008	HAO membership increases to 93 members including seven residential hospices

2008	The provincial PCIP changes its name to the Ontario Cancer Symptom Management Collaborative
2009	First collaborative conference hosted by the HAO and OPCA – “One Vision One Voice, the 2009 Annual HPC Conference”
2009	Provincial HPC Consortium forms between Provincial End-of-Life Care Network, CCO, the Ontario College of Family Physicians, the Ontario Association of CCACs, HAO, OPCA and other organizations at the HPC Provincial Think Tank to advance HPC across the province

Connecting the Dots: Ontario’s HPC Timeline and a Shift in Federal Priorities

The following sections define windows of time in the development of HPC in Ontario, illustrating how key HPC events have occurred alongside federal shifts in priorities and funding strategies. It will be shown that certain events at the provincial level have coincided with changes brought about by the federal government.

Late 1970s and 1980s: The Foundational Years

Dr. Balfour Mount, a cancer surgeon turned palliative care specialist, is widely credited as starting the HPC movement in Canada in 1974. According to a key informant, it was Dr. Mount’s advocacy work that prompted health professionals in Southern Ontario to inventory the state of HPC in the province and join forces for the purpose of advancing the specialty. Although Ontario lagged behind other provinces in HPC development, the 1980s brought with it a decade of laying the groundwork for HPC, both in Ontario and throughout Canada, with the establishment of the Palliative Care Foundation in 1981 (which later became the Ontario Palliative Care Association [OPCA]), the inception of the internationally renowned Journal of Palliative Care and the development of a research and educational institution devoted to HPC at the University of Ottawa – one of the first of its kind in Canada. These events coincided with a paradigm shift in the Canadian Health Care System as a whole. According to the Canadian Hospice Palliative Care Association (CHPCA), the health care system was adding new terms to its vocabulary in order to accommodate changes in the philosophy of care. As a result, new terms including ‘chronic’, ‘geriatric’ and ‘palliative’ were being used to describe the trajectory of a patient’s life-course [5]. By the end of the 1980s, a second HPC provincial organization was formed – the Hospice Association of Ontario (HAO). Ontario is the only province to have two provincial organizations. The two organizations have co-existed in the HPC movement, both representing different memberships and foci. For example, the HAO represented mainly physicians, whereas the OPCA had a wider range of health professionals as members. In 2009 they joined forces to host their first collaborative conference.

1990s: The Ontario Government Starts to Take Notice of HPC

As demonstrated by the timeline, few HPC milestones occur in the 1990s. It is only in 1992 that the Ministry of Health (later renamed the Ministry of Health and Long-Term Care in 1999) provides funding for the purpose of increasing the educational capacity. Specific initiatives developed through the funding include: education initiatives for interdisciplinary providers, education for family physicians, support and maintenance of hospice volunteer

visiting programs, and the establishment of regional pain and symptom management teams. Education activities and supports were implemented prior to the shift of care from acute settings, such as hospital, to community care which was heightened in 1995 as part of major health care reform in Ontario. In 1995 Community Care Access Centers (CCACs) were developed, which enforced the national momentum towards delivering specialized care within the community and increasing opportunities for patients to remain at home even at the end of life. As part of their mandate, the CCACs offer ‘a one-stop shopping’ so patients can access a variety of community-based services in one place. With the creation of the CCACs, Ontario also implemented a managed care model, whereby services are contracted out by CCACs through a bidding process. Managed care thus encourages competition between providers for acquiring the contract, with the intent that competition provides an incentive for high quality care. The managed care model is still employed today, although critics have argued that there are unfavourable consequences of the system. For example deterioration in the quality of home care is seen as provider organizations (both non-profit and for profit) compete for contract prices. Ontario is the only province in Canada that has implemented a model of managed care.

Through the *Ontario Hospital Services Restructuring Commission* (1996-2000), many sites for acute care were closed, furthering the transition from care delivered institutionally to care delivered within the community and at home. Ultimately, it was through this shift that greater emphasis was placed on developing strong community and home HPC programs.



Early 1990s: Rural Progress Begins

Policy efforts to address fundamental rural health delivery challenges of access and quality, and specifically addressing HPC services, only began in the early 1990s, lagging behind the rest of the province by almost two decades! As a key informant stated, “*Rural care is like a big black hole. It really is.*”

Consistent with the shift to community-based care, the MOHLTC funded educational and training initiatives in 1992 that improved the ability of care providers to offer palliative care. These initiatives greatly benefited generalist health care professionals working in rural areas; however, these same care providers have noted that supplying quality palliative care was hampered by a lack of resources, including home care services.



The Canadian Palliative Care Foundation formed in 1991, with the first office opening in 1994. The Foundation would later be renamed as the Canadian Hospice Palliative Care Foundation in 2001.

At the federal level, inquests into euthanasia were being made in the early 1990s and an instrumental report with respect to HPC in Canada was put forth in the 1995 – *The Senate Committee Report on Life and Death*. A follow-up report was completed in 2000 entitled *Quality End of Life Care: The Right of Every Canadian* (commonly referred to as Carstairs’ report), which was produced through the 2000 Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology.

2000-Present: Stakeholders Unite for HPC

Despite the lack of the HPC progress in the early to mid-1990s, major headway is made by Cancer Care Ontario (CCO) and various stakeholders beginning in the late 1990s with the development of the Palliative Care Integration Project (PCIP). PCIP is a HPC intervention that promotes common assessment and procedures. The success of the smaller PCIP project in Southeastern Ontario leads to further development and implementation of the Provincial PCIP (PPCIP) – a joint effort between the MOHLTC and the CCO across the province of Ontario in 2006. It should also be noted that in 2004, CCO identified HPC as a priority area. The support for HPC from the CCO was viewed as instrumental to the growing acceptance for HPC.

“...Cancer Care Ontario has taken a significant leadership role; even though it is focusing on cancer palliative patients, the tools and the approach can certainly be expanded to other palliative populations” (key informant)



Ongoing Rural Developments:

In 2006, funding from the Ministry of Northern Development, and the Northern Prosperity Plan lead to some increased attention to northern HPC, with the establishment of three residential hospices. Additional support was given for the development of the Northern Ontario School of Medicine, as well as extensions to Northern Ontario hospitals and to the implementation of a telemedicine program. While these initiatives do not cater to HPC specifically, their general role in Northern Ontario health care cannot be neglected.

In 2007, Dr. Mary Lou Kelley, a researcher from Lakehead University publishes a paper entitled: “Developing rural communities’ capacity for palliative care: A conceptual model” in the Journal of Palliative Care, putting forth a rural model for HPC development.



The two senate reports (*Of Life and Death* and *Quality End of Life Care: The Right of Every Canadian*) lead the Federal Government to put money towards HPC for all provinces through the 2003 Canadian Federal Health Accord.

Ontario developed the End-of-Life Care Strategy in 2005, improving access to home and community care HPC services. The End-of-Life Care Strategy also put emphasis on developing the role of hospice volunteers and increasing funding for residential hospices across Ontario.

The MOHLTC went on to develop 14 Palliative Care Networks in 2005, one for each of the regional health integration networks (known as Local Health Integration Networks, or LHINs). Two years later, in 2007, the MOHLTC announced funding for the *Aging at Home*

“Obviously the End-of-Life Care Strategy was incredibly significant in the sense that...there had never been targeted funding for palliative end-of-life care in Ontario for actual service delivery until the October 2005 End-of-Life Care Strategy funding.” (key informant)

Strategy. Although not entirely specific to HPC, the recognition of the importance of a care continuum across care settings by the MOHLTC further confirms the provincial government's commitment to improving HPC services. The initiative promised \$1.1 billion over four years to assist the LHINs in providing home care (many LHINs did not support HPC with those funds). Monies from the MOHLTC increased in 2007, and as a result, funding expanded from nine hospices to 15 organizations. Furthermore, an increase in the HAO's membership in 2008 affirms a growing response and acceptance of HPC at the community level. Another significant step in the HPC movement was marked by the first-ever HPC conference hosted in collaboration by the HAO and the OPCA in 2009. This suggests that these two stakeholder groups, which have been scrutinized for working independently over the years, are beginning to join forces. Also in 2009, a number of stakeholder groups, including the Provincial Hospice Palliative Care Networks, the Ontario College of Family Physicians, the HAO and OPCA, and Cancer Care Ontario, joined together to form a provincial HPC consortium at the HPC Provincial Think Tank. This collaboration shows that multiple stakeholders have begun to work together towards a common goal for advancing HPC across the province.



Many other key federal events and reports were produced in the following years, including:

- In 2001, the Secretariat on Palliative and End-of-Life Care was established and led by Senator Sharon Carstairs
- The Canadian Hospice Palliative Care Association releases *A Model to Guide Hospice Palliative Care Based on National Principles and Norms of Practice* (2002)
- Two reports assessing the health status of Canadians and the health care system are published: ¹The Kirby Report: *The Health of Canadians – The Federal Role* and the ²Romanow Report: *Commission on the Future of Health Care in Canada*. Both of these reports comment on the state of HPC and offer recommendations.
- In 2004 the Primary Care Health Transition Fund begins to provide monies to advance primary care including HPC initiatives and The Compassionate Care Benefit is enacted
- Senator Carstairs also published *Still Not There. Quality End-of-Life Care: A Progress Report* in 2005 as a follow up to her earlier report
- In 2006 the Primary Health Care Transition funding ends
- In 2007 the Secretariat on Palliative and End-of-Life Care is disbanded, six years after its inception!



Increased money for Rural HPC:

Pallium was an educational initiative funded through the federal Primary Health Care Transition Fund, which ran from 2004 to 2006. In Ontario, this initiative enhanced resources for rural practitioners in palliative care, providing increased financial support in the development of palliative care knowledge.

In 2006, the federal government also announced funding for the development of three northern residential hospices in Sudbury, Sault Ste. Marie and Thunder Bay. However the Thunder Bay hospice has not been constructed due to a lack of operating funds.

Building Blocks of HPC: Key Organizations and People

HPC development in Ontario would not have been possible without the efforts of many organizations and individuals. Key informants repeatedly noted both the formal and informal organizations including dedicated volunteers and advocates. It would be impossible to provide a list of names to recognize these countless organizations and key players in the HPC movement, however, there are a number of individuals who have been recognized as pioneers including:

- Dr. Elizabeth Latimer, a palliative care physician in Southern Ontario. She authored two handbooks for patients and families – *Easing the Hurt* and *Miles to Go* – of which over 100,000 copies have been distributed across Canada.
- Dr. Larry Librach, a palliative care physician in Southern Ontario who has dedicated over 30 years of his career as both a palliative practitioner and advocate.
- Barb Linkewich, trained as a nurse and instrumental in developing regional pain and symptom management teams, education and research, has worked as an HPC advocate in Northwestern Ontario and in First Nations communities.
- Chris Sherwood, who is a former HPC consultant for communities in Southern Ontario, and is a past president of the Ontario Palliative Care Association, having served as a member on the board of directors since 2002.

“Locally, I can think of we- the volunteer community agencies that are struggling really hard to serve their very local community. Although that doesn’t have a large impact provincially or nationally, it certainly does locally. The monies that flow into these little, very volunteer-driven programs really make a difference.” (key informant)

“Hospice palliative care has always been a grassroots movement, i.e., the people who are at the front line see that there is a need and take their only personal efforts sometimes beyond their job description to fill gaps they see need to be filled.” (key informant)

Important Outcomes and Ongoing Challenges

Ontario residents described a lack of integration, coordination and communication in HPC in 1999/2000 [6]. With an increased focus on HPC and the development of networks for integration and delivery of care, HPC has evolved to better meet the MOHLTC’s goals of coordination, access, quality and efficiency. As such, a major success has been the ongoing development of a framework for guidance and continued communication through the HPC Networks. As one respondent stated: *“[HPC] Networks- that, I think, is an amazing thing. ...when I look back to...when I began working in end-of-life care, there was no co-ordination. Nobody was really even talking about it. When I look at the [HPC] Networks and the possibilities that lie within those, I see great hope.”*

It is important to recognize that the effectiveness of HPC Networks has yet to be examined due to their recent implementation. As exemplified by the respondent quoted above, while there is great hope, an evaluation of the Networks still needs to happen.

Additional challenges in moving forward with the development of HPC were often cited as a lack of clarity in the language and definition of HPC. Issues around identifying who is palliative and when HPC should be discussed in the care plans of patients arose from a lack of capacity and knowledge by health professionals about the scope and purpose of HPC. However, it should be recognized that these issues are not solely specific to Ontario but also exist in other provinces. Also, there are no common approaches to HPC across hospital, long term care and home care settings, which are major sites of death.

“...in the hospice palliative care community, there has been major discrepancies in how people communicate the so-called common language of hospice palliative care...” (key informant)

Another challenge that was noted was a lack of co-ordination in, and multiplicity of, HPC initiatives across the province. One of the most glaring sources of multiple initiatives was attributed to the presence of two provincial organizations; the HAO and the OPCA. However, ongoing collaborations between these two organizations have brought them closer, and their official union as one organization is currently in the works.

“[Challenges] that exist in that there are far more people who need to have access to hospice palliative care than are actually being identified as that...That partly goes back to the issue that everyone is waiting to be deemed “palliative.”” (key informant)

Although participants voiced concerns about the lack of coordination, integration and organization of HPC services, they did commend efforts and progress. As mentioned, a number of stakeholder groups have recently come together to build a provincial system of integrated HPC that is accessible to all Ontarians. In addition, as noted by an HPC advocate, there is no uniformity because there is no national HPC strategy. Further, the provincial EoL strategy is not enduring given that financial support is time limited and may expire or decrease. With no guarantee for renewal given funding is annualized, the sustainability of resources is compromised.

Epilogue

Further Information

To learn more about the team’s research or to be updated about this comparative study please visit <http://www.nursing.ualberta.ca/tast/>. As mentioned, a limitation of this study is its reliance on informal or disparate forms of information. For this reason, we ask you the reader to bring any discrepancies or any information that we may have missed to the research team by contacting Lily DeMiglio at demigllf@mcmaster.ca.

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Figure 1: Ontario Local Health Integration Network Boundaries. Map available at: <http://www.lhins.on.ca>

