

## **A Timeline of Palliative Care Policy and Practice in British Columbia, Canada**



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## **Introduction**

The development of palliative care services in the Canadian province of British Columbia (BC) has been shaped by several social, political and geographical factors. The province is currently home to a rapidly aging population (Ministry of Community Services, 2007) which is impacting the way in which health planning is being managed due to increased demand for aging related services. Further, the challenging topography of BC and consequently uneven spatial distribution of populations have led to a significant amount of variance in how palliative care services are delivered across different regions of the province.

An important piece of context in BC is that in 2001 five regional health authorities were established in order to administer services on a regional basis. This restructuring was done with the hopes of creating a:

“system that is: equitable, with access to a coordinated range of local, regional and provincial services for all British Columbians, regardless of where they live in the province; effective and efficient, with services coordinated within regions large enough to recruit and retain health professionals and achieve economies of scale; governed by strong leaders, with board members chosen for their leadership skills, decision-making abilities and willingness to be accountable for desired outcomes; and accountable with clearly articulated and conscientiously monitored performance measures and targets” (BC Ministry of Health, 2008).

An outcome of this regionalization is that palliative care has been prioritized differently throughout the province, including across urban and rural regions. One authority, the Fraser Health Authority, has significantly prioritized palliative care. The outcome of this is that the mostly urban areas it serves have more extensive palliative care provisioning than do many of the communities serviced by the other regional authorities (see Cinnamon et al., 2008).

In 2006 the BC Ministry of Health released a framework on palliative care (BC Ministry of Health, 2006). In this document it is outlined who holds what responsibility for palliative care in the province. Three groups are identified, each of which plays a role in advancing palliative care policy and practice:

- BC Ministry of Health (responsible for: legislative changes to improve end-of-life care [e.g. regulating residential hospices], funding of health system, funding health authorities to deliver services, funding essential services [e.g. physicians, ambulances, PharmaCare], ongoing monitoring and measurement of end-of-life care and its use)
- Health Authorities (responsible for: organizing and delivering health services, hiring staff to deliver home & residential care, contracting out home & residential care, assessing regional end-of-life care, establishing integrated networks of care, enhancing services)
- Community groups (responsible for: psychosocial support and bereavement)

What must be understood is that the regional health authorities have responsibility over delivering palliative care and because of this there is limited opportunity to create provincial level policies.

The purpose of this report is to characterize the development of palliative care in BC and in doing so establish a timeline for major milestones. This work was conducted as part of a larger project which has aimed to establish timelines for the provincial jurisdictions of BC, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, and Prince Edward Island with a focus specifically on rural palliative care policy and practice. As there have been few initiatives specific to rural BC this report focuses on the province more generally. A review of the grey literature (e.g., ministry reports), of newspaper reports, of the Hansard files (the verbatim transcriptions of provincial parliamentary debates), and interviews with seven key informants who have extensive palliative care expertise in the province form the basis of what is shared herein. The key informants participated in phone interviews with Dr. Valorie Crooks in the spring of 2008. Quotes from the key informants have been included throughout this report in order to convey key points.

## Key Milestones

Many milestones and events in the development of palliative care in BC were identified by key informants and through review of the grey literature. These include:

- 1978/79 - BC Ministry of Health established 'Hospice Project' out of which Victoria Hospice and Vancouver Home Hospice were opened with provincial monies
- 1980 - Victoria Hospice opens
- 1981 - Vancouver Home Hospice opens
- 1984 - BC Hospice Palliative Care Association (BCHPCA) is incorporated
- 1995 - Canuck Place opens as North America's first free-standing children's hospice
- 1996 - University of British Columbia's (UBC) Division of Palliative Care is founded in the Department of Family Practice
- 1998 - BC Cancer Agency Pain & Symptom Management/Palliative Care Program is started
- 2001 - BC Palliative Care Benefits Program, including Palliative Care Drug Program and Medical Supplies and Equipments Benefits, is implemented
- 2001 - Fraser Health Authority establishes the most comprehensive regional palliative care program in BC
- 2002 - 'Palliative Care Norms of Practice' document is released based on 10 years of consultation across Canada
- 2002-06 - Pallium Project (run by Health Canada through Primary Health Care Transition Fund) in BC hosts regional palliative care workshops
- 2004-09 - Canadian Institutes of Health Research fund 9 palliative care research teams, 4 are housed in BC
- 2006 - inclusion of the federal Compassionate Care Benefit within the provincial legislation of Employment Insurance
- 2006 - release of the provincial End of Life framework by the BC Ministry of Health.

It was after 2000 that key milestones in BC were informed by activities taking place nationally through advocacy by the CHPCA and the federal Palliative Care Secretariat. Also noteworthy is that the Pallium Project initiative is the only one that was specifically aimed at palliative care in rural and remote areas. In *Appendix 1* a detailed timeline for the province is included.

“I think that some of the offerings of the Pallium Project...have been quite significant. They funded our BC Nurseline Project... They've developed quite a lot of tools and resources...”

“What they did was Victoria Hospice just said, ‘Well, what do we do if we have a hospice, sort of, entity that lives in a building and does this from this building?’ And they said in Vancouver, ‘Well, what do we have if we have a hospice entity that doesn't live in a building, that's more of a home hospice project?’”

“If you think about the Norms of Practice, I'd say it was people who were in leadership positions across Canada who recognized an opportunity for our country to really come forward and say in a way that was very significant, ‘This is going to happen.’”

“...having Canuck Place here is a major milestone. There was leadership there that made that happen in a way... It only could have happened here in Van [Vancouver] at that time.”

## Shifting Priorities

“I think another key certainly was the Palliative Care Plan P. program – benefits program – because that had come after a number of years of issues for people at home and, you know, the government stepped ahead and that’s been a dramatic help to patients.”

Reviewing the Hansard files from 1970 provided a wealth of information regarding both palliative care priorities in BC and also shifting concerns over time. It was clear that in the 1970s palliative care was not viewed as a priority by the provincial government. By the 1980s this had changed. At this point members of parliament had started to talk about palliative care in the legislature. While there was, by this time, increasing recognition of the need to formally provide palliative care to British Columbians, there remained among some a view that such care was already being adequately provided in the form of hospital-based acute care and that palliative care did not necessarily require stand alone facilities such as hospices. Interestingly, personal stories about people not receiving needed palliative care were used to initiate dialogue about palliative care in the legislative sessions. A key issue of debate regarded whether or not palliative care was institutionalized care that needed to be provided by the government or if was family caregiving provided in the home.

“With the positioning of the Framework, basically what they’ve said is, ‘This care needs to be available for everyone who’s dying, not just cancer patients.’ So, it’s like, they’ve said, ‘You know, we don’t want this just to apply to cancer patients, we want it to apply to everybody who’s dying, everybody who needs it.’ But they haven’t put any resources with that.”

By the late 1980s it was recognized that formal palliative care services needed to be established. In the 1990s focus shifted to discussing funding for palliative care. Certainly, given the focus at the national level on system restructuring and rationalization, it is not surprising that this led to open debate about whether or not funding for palliative care was a priority. Noteworthy is that discussions shifted away from whether or not formal palliative care was needed – in that there seemed to be an understanding that the provincial government needed to provide care – and moved onto how it would be funded. More recently, in the 2000s, references to palliative care have focused mainly on developing specific initiatives such as the BC Provincial Framework for End of Life Care, the federal Compassionate Care Benefit, and the palliative care Pharmacare program. The implementation of the Pharmacare ‘Plan P’ benefits program, which improved people’s abilities to receive palliative care services in the home through providing pharmaceuticals, also marked a shift for the government where the priority had previously lied with building free standing hospices to now facilitating in home-based palliative care options.

“I think that the leadership is coming from the regional programs and from the Cancer Agency and everyone else and try to push the Provincial Government into policy.”

The need for palliative care has long been championed by cancer organizations, thus making cancer-focused care a significant priority. The BC Cancer Agency has aimed to improve the quality of life of patients living and dying with cancer. This focus on cancer care extends beyond BC and has long been a source of contention in palliative care circles (see McKenzie, 1998), in that cancer is but one of a number of conditions that people may ultimately access palliative care services to manage. Many of these concerns have been managed in BC through the prioritization of palliative care for all dying individuals through the inception of organizations such as the BCHPCA, Victoria Hospice, and Canuck Place as well as improved education and interdisciplinary communication.

## Key People and Organizations

Two organizations in particular were frequently cited by key informants as playing an important role in palliative care in the province, these are *Victoria Hospice* and the *BCHPCA*. *Victoria Hospice* was started as a palliative care demonstration project by the BC government in 1980. One informant summed up its role in the provision of palliative care as influential at the international, national, and provincial levels as many palliative care leaders practice and research there. The mandates of both organizations have evolved over time as they have begun to play more important advocacy roles and they each continue to evolve with changing leadership. The *BC Cancer Agency* was also noted by several key informants as a key organization in the province.

“I think, still, one of our real successes is the collaborative nature of what we do in BC compared to other places, where it’s more competitive. We really do have a wonderful team mentality here. And I think that’s going to ensure our long-term success if we could just figure out how to make it work for us.”

It is clear that numerous individuals have played key roles in shaping palliative care in BC. Several *practitioners and researchers* in the province have provided leadership that has brought about key policy and practice initiatives. *Family caregivers and local hospice volunteers* were also identified as playing an important role in palliative care leadership and provisioning in the province. This was cited as especially being the case in more rural and remote areas of the BC. The presence of a *palliative medicine program at UBC*, those involved in leading it, and those who have been trained by it are also important actors in shaping palliative care context in the province.

“That [BCHPCA] has been our advocacy force. I can do what I can in a policy level, but I can never act as, sort of, an outside, external advocate. And they can do wonderful things and take politicians to lunch and do all sorts of things that I can’t do.”

Another important piece of context that has evolved greatly over time in BC is the *development of research capacity* regarding palliative care. Numerous key informants cited BC as a place where important palliative care research is taking place. Researchers recognized internationally for this work are based in BC. For example, it was frequently cited that several of the Canadian Institutes of Health Research New Emerging Team grants specific to palliative care are housed in BC and that this exemplifies research excellence in the province. At the same time, the funding of these teams will stop in 2009 so this leaves some uncertainty regarding the role of research in the province’s palliative care landscape over the coming years.

“...there is a tremendous amount of research happening here with the NET [New Emerging Team] grants and so on, so there’s a real richness and a depth here.”

“I think the Norms document really gave us a common language and a very useful way to look at organizing, you know, programs and practices in palliative care – kind of established the foundation for that.”

“[We’re] working with the rural care providers on Vancouver Island to increase their skills and their capacities and to teach them how to teach in their own communities to further increase that capacity. We started with ten different [rural] communities...and actually, helped Nanaimo to become more, sort of, a teaching resource for them as well, too.”

### **Important Outcomes**

When asked to reflect on the successes related to policy and practice in the province of BC key informants frequently mentioned the following:

- The development of a knowledgeable leadership over time.
- The sustained focus and attention on palliative care by certain individuals.
- The community galvanization around palliative care, particularly in certain rural and remote areas, which has made it into a local priority in some areas of BC.
- The increased provincial coordination over time, notably with the establishment of the health authorities and also some Ministry of Health committees.
- The number of hospices that have opened over the past decade.
- The development of a common language resulting from establishing provincial and federal level policies.

The outcomes of these successes vary across the province. For example, they have had less of an impact in rural and remote areas where palliative care has yet to become a major priority. Specific to these areas is that an outcome of a lack of formal prioritization has been a reliance on local fundraising and significant amounts of volunteer labour in order to support local palliative care initiatives.

## Remaining Challenges

Key informants were asked to comment on obstacles to policy and practice progress in BC. Those most frequently identified are (note that these are not in a ranked or priority order):

- That there is no funding or accountability specifically for palliative care within the health authorities (i.e., palliative care is not its own budget line).
- That palliative care is not considered to be a provincially-funded core service.
- That the BC Ministry of Health’s consultation group on palliative care (created in 2004) does not have the capacity to make real change due in part to being situated under the home and continuing care umbrella.
- That many decision-makers have not been personally exposed to palliative care.
- That there continues to be an overly great variance in palliative care services across communities.
- That physician funding has been frozen since 2001 so it is not possible to add hours specific to palliative care.
- That there is a lack of data to support new initiatives.
- That there is a lack of provincial vision.
- That there is no provincial strategy for educating and building a palliative care workforce.
- That much of the focus is still on cancer care.
- That the overall reliance is still on providing specialist care (i.e., there needs to be support for palliative care provision within primary care).
- That there are important issues of definition (what is palliative care, at what point is someone thought to be in need of accessing palliative care?) and also naming (terminal vs. hospice vs. palliative) that hinder care provision.
- That attitudinal marginalization regarding death and palliation among public and health care providers still exists.
- That there remains uncertainty about whether the focus should be on care in the home or care in institutionalized settings.
- That BC currently lacks a palliative care political champion.

“...sometimes when we create these subcommittees and unique little working groups, we tend to think of end-of-life as a program, and we align it along with acute care and home and community care and stuff like that. But really, end-of-life spans many services. It’s kind of like primary health care and end-of-life. They don’t really fit. They’re not a standalone program, but they’re part of the full continuum, and I think that can be a bit of a barrier or challenge when we want to define it for its uniqueness. But it really spans many services.”

“...the other thing that poses a challenge for us too is the number of different ethnic groups we deal with here. And, you know, are we doing that well, do we do things in people’s language of origin, which is what they want at end-of-life, right?”

“The health authorities cannot raise capital funds. That’s not in their mandate. They can’t do fundraising for capital, so they’re dependent on the communities right now to build hospices.”

“One of the populations that is locally overlooked in our province is the Aboriginal folk. And I’ve done some work on that... The last three years, I’ve done proposals to the Ministry of Health when they’ve called for proposals for Aboriginal health...with my leadership team looking at how we could partner with the band leaders and they’ve all signed on, [which] is important. But the issues that seem to come forward as important health issues for First Nations are not end-of-life.”

“The real challenges... and the opportunities, [are] certainly in things like telehealth... Opportunities to connect to that rural nurse [or] the physician... They need what we call ‘just in time education’, so to be able to call and talk to somebody, get some good advice, you know, you can’t have experts everywhere, but you do need expertise...access to expertise”

### **Rural and Remote Remaining Challenges**

While most key informants foremost acknowledged the above listed general challenges, they did acknowledge some challenges specific to rural and remote BC communities:

- That there is a lack of critical mass in rural and remote areas to have specialists on site (this necessitates creativity in providing care in these areas).
- Topographic challenges such as BC’s significantly mountainous terrain and also the islands, both large and small, that run along its coast.
- A dispersed population which results in extremely large areas of the province being home to very small numbers of people.
- The lack of consultation with Aboriginal peoples about end-of-life and palliative care planning.
- The need for local consideration in health care programming and planning despite the regionalization of decision-making.
- The under-use of technologies such as telehealth.
- The lack of local leadership in some rural and remote areas.
- That needs assessments for palliative care in rural and remote communities are based on the number of home deaths and are over-representing the success of rural palliative care availability and quality.
- The lack of vision with regard to alternative programs such as integrative homecare teams.
- The difficulty of making palliative care accessible to members of a number of cultural communities including Aboriginal peoples.
- The lack of fundraising potential due to limited local populations.
- The difficulties in attracting and retaining trained palliative care practitioners and healthcare workers more generally.

## Summary

As noted in the introduction, the purpose of this report has been to characterize the development of palliative care in BC and in doing so establish a timeline for major milestones. Drawing on the findings of interviews conducted with seven key informants in BC and reviews of the grey literature and Hansard files, summarized herein were the province's key palliative care policy and practice milestones, shifting priorities regarding palliative care, key people and organizations that have supported the development of palliative care, outcomes of palliative care policy and practice initiatives, and remaining challenges to be addressed both in general and specifically for rural and remote communities. The remaining challenges which have been identified do, in fact, provide numerous suggestions for ways ahead in strengthening palliative care across the province.

## Further Information

Academic posters summarizing the findings of this study have been presented at two conferences. These posters are included in Appendices 2 and 3. If you wish to see these posters at a clearer resolution please contact the report author or visit [http://www.nursing.ualberta.ca/tast/Projects/CAHSPR\\_BC.pdf](http://www.nursing.ualberta.ca/tast/Projects/CAHSPR_BC.pdf) and [http://www.nursing.ualberta.ca/tast/Projects/Archer\\_Crooks\\_Poster.pdf](http://www.nursing.ualberta.ca/tast/Projects/Archer_Crooks_Poster.pdf). The findings of the comparative study will likely be published in academic journal articles. For information on publication details or article topics please contact the report author. Updates about the comparative study are also available online by visiting: <http://www.nursing.ualberta.ca/tast/>. While this study was under way the Canadian Institute for Health Information released the report *Health Care Use at the End of Life in British Columbia*. This report contains a wealth of information regarding the distribution and uptake of formal palliative care services in the province and may serve as a useful point of reference for those looking for more information about the BC context (see CIHI, 2008).

## Acknowledgements

The key informants who contributed their time and knowledge to this study are greatly thanked. Laura Archer worked as a research assistant on this study; her contributions have been invaluable. The larger comparative study to which this report contributes was funded by a Canadian Institutes of Health Research Interdisciplinary Capacity Enhancement Grant co-led by Drs. Allison Williams (McMaster University) and Donna Wilson (University of Alberta). Co-investigators on the research team are: K. Brazil, D. Brooks, N.K. Chappell, D.S. Cloutier Fisher, W. Duggleby, R.L. Fainsinger, L. Fillion, D.M. Goodridge, C. Justice, S.J. Kaasalainen, M.L. Kelley, K.A. Kovacs Burns, B.D. Leipert, M. Maclean, D. Marshall, V.H. Menec, J.L. Richards, C.J.M. Ross, A. Taniguchi, R.E. Thomas, C.D. Truman, and K.F.B. Willison. To learn more about the team's research or to be updated about this comparative study please visit: <http://www.nursing.ualberta.ca/tast/>.

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## Appendix 1

### Detailed Timeline of Palliative Care Events in BC

Identified turning points

National origin

Explicitly described as not major, not unique, and/or not specific to palliative care or to BC

1935	May 21 <sup>st</sup> - BC Cancer Foundation is incorporated
1974	Cancer Care Agency of BC (now BC Cancer Agency) was established when the Provincial Government takes over cancer care and treatment from the BC Cancer Foundation
Late 1970s	Royal Columbian Hospital in New Westminster opens a palliative care program (it closed within a few years because it received no provincial funding)
1978	Victoria Association for the Care of the Dying (an advocacy group) formed
1978/79	BC Ministry of Health establishes 'Hospice Project' out of which Victoria Hospice and Vancouver Home Hospice were opened with provincial monies
Early 1980s	St. Mary's Hospital in New Westminster opens a palliative care unit
1980/81	Lion's Gate Palliative Care starts-up using no provincial funding
1980	Victoria Hospice opens
1981	Vancouver Home Hospice opens
1982	first provincial symposium on hospice care is held in Victoria; met again in Kamloops in 1983; ultimately led to creation of the BCHPCA
1984	BCHPCA incorporated
1984	Health Canada releases 'Pain Monograph', a foundational document for palliative care nationally
1985	BC Ministry of Health creates a committee to establish a blueprint for palliative care (not much happened as a result)
1988	BC Bereavement Helpline established to provide resources and help to the public and the bereaved
1989/90	formation of the Canadian Hospice Palliative Care Association (CHPCA)
1991	CHPCA bi-annual meeting is held in Vancouver (co-sponsored by BCHPCA and served as a gathering point for people involved in palliative care across BC)
1991	May's Place hospice opens in Vancouver's downtown eastside (has 6 beds, continues to function)
1993	Friends For Life is incorporated to meet the needs of people dealing with and dying from HIV/AIDS
1993	BC Ministry of Health creates a committee on palliative care drugs for patients at home (led to the 2001 palliative care benefits program)
1995	Canuck Place opens as North America's first free-standing children's hospice
1995	Rotary Hospice House opens in Prince George
1996	strategic palliative care teams are funded by the province

1996	UBC Division of Palliative Care is founded (in Department of Family Practice)
1997	Dr. Peter Centre Day Health Program opens its doors in an old wing of St. Paul 's Hospital (note: not exclusively focused on palliative care)
1998	BC Cancer Agency Pain & Symptom Management/Palliative Care Program starts
1999	Victoria Hospice partners with BC Cancer Agency to create a network for palliative care across Vancouver Island, provides training and support to providers in more rural/remote areas
1999	'Learning Centre for Palliative Care' formed through Victoria Hospice (now through BCHPCA) to provide palliative care education and advocacy
1999	BC Medical Association creates committee on palliative care and gerontology
2000	Lois Fish Palliative Society is established to help to build and provide a comprehensive and integrated palliative care system (note: no longer functioning)
2001	Griefworks BC begins as a partnership between Children & Women's Health Centers of BC & Canuck Place Children's Hospice
2001	February 1 <sup>st</sup> – BC Palliative Care Benefits Program including Palliative Care Drug Program and Medical Supplies and Equipments Benefits is implemented
2001	announcement of the formation of a committee to establish the framework for end of life care released in 2006
2001	December- Establishment of 5 regional health authorities in BC
2002	Establishment of fully funded hospice palliative care program in the Fraser Health Authority
2002	'Palliative Care Norms of Practice' document is released based on 10 years of consultation across Canada
2002	'BC Palliative Care Discussion Paper' is released, served as a precursor to the 2006 framework document
2002	St. Michael's hospice opens
2002-06	<u>Pallium Project (run by Health Canada through the Primary Health Care Transition Fund), in BC hosts regional palliative care workshops and funds the development of a telenursing model across the Western provinces</u>
2003	Crossroads Inlet Centre (the first Integrated Hospice/Affordable housing opens)
2004	BC Ministry of health creates 'end of life standing committee', which is the palliative care policy group and includes representatives from all health authorities
2004	<u>Canadian strategy for cancer care</u>
2004	<u>Four CIHR-funded NET's focused on palliative care are established in BC</u>
2005	April 1st- Pharmacare fully funds and administers Plan P as portion of the BC Palliative Care Benefits Program and local health authorities retain medical supply and equipment portion of the program
2005	BC Nurseline (a telenursing phone line) established in the Fraser Health

	Authority, can serve as first-responders for palliative care
2006	<u>Inclusion of Compassionate Care Benefit within the provincial legislation of Employment Insurance</u>
2006	Release of a provincial End of Life framework by the BC Ministry of Health.
2006	<u>provincial working group for Canadian strategy for palliative care formed</u>
2007	<u>Canadian partnership against cancer</u>

Appendix 2

Timeline Summary – Poster View

## FROM PAST TO PRESENT: AN HISTORICAL REVIEW OF PALLIATIVE CARE POLICY AND PRACTICE IN BRITISH COLUMBIA

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### OVERVIEW

In order to effectively address current health system challenges and operationalize a sustainable system it is useful to look back on how we have ended up in our current state of service delivery. An approach to doing this is to conduct an historical review of policy and practice. In this poster we present such a review specific to palliative care British Columbia (BC), highlighting a limited number of key events in the province. We add commentary to this timeline to draw attention to particular events and outcomes. We conclude by considering the implications for uptake and implementation of the BC Ministry of Health's 2006 framework for palliative and end-of-life care. Overall, there are two learning objectives: (1) to inform readers about the historical roots of current palliative care policy and practice in BC; and (2) to encourage readers to consider how past policies and initiatives across the health system shape contemporary practice and delivery.

### STUDY DESIGN

- 6 step analysis process: (1) summarize past events; (2) contextualize; (3) identify relevant concerns; (4) determine policies; (5) identify outcomes; and (6) identify future threats and opportunities (see Springate-Bagniski & Soussan, 2001)
- review of grey literature documents identified from strategic searches and through key informants
- key informant interviews (n=7) conducted with people who have significant palliative care expertise and/or knowledge in BC
- review of legislative Hansard files from 1970s onward, looking for mentions of palliative care
- keyword search of BC newspapers for articles featuring stories about, or of relevance to, palliative care

### ACKNOWLEDGEMENTS

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- Thanks to Laura Archer who worked as a Research Assistant on this sub-study.
- For more information: crooks@sfu.ca

### BRITISH COLUMBIA'S PALLIATIVE CARE POLICY & PRACTICE TIMELINE: KEY EVENTS

"What they did was Victoria Hospice just said, 'Well, what do we do if we have a hospice, sort of entity that lives in a building and does this from this building?' And they said in Vancouver, 'Well, what do we have if we have a hospice entity that doesn't live in a building, that's more of a home hospice project?'"

"Well, I think that, you know, having Camex Place here is a major milestone. There was leadership there that made that happen in a way... It only could have happened here in Van (Vancouver) at that time."

"If you think about the Norms of Practice, I'd say it was people who were in leadership positions across Canada who recognized an opportunity for our country to really come forward and say in a way that was very significant, 'This is going to happen.'"

### TIMELINE LEGEND:

BLUE – key event  
 BURGUNDY – milestone identified by key informants  
 ○ – quotation from key informant interview

### IMPLICATIONS

- Momentum regarding palliative care has been increasingly growing since the late 1990s which is the point at which several key milestones took place.
- Key informants noted that BC has played leadership in certain aspects of palliative care both nationally and internationally.
- Several events, both small and large, led to the development of BC's 2006 framework for palliative and end-of-life care. There was recognition among the key informant group that although this document remains important, it lacks the detail (especially regarding guidelines) to be translated into policy, particularly beyond the local/regional scale. There is a desire among this group to see provincial standards be put in place.
- Though considered a primary health care priority by the BC Ministry of Health, hospice and palliative care programs are being increasingly subsidized through private partnerships.

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Appendix 3

Gendered Implications – Poster View

## A TIMELINE OF PALLIATIVE CARE POLICY AND PRACTICE IN BRITISH COLUMBIA: CONSIDERING GENDERED IMPLICATIONS

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Department of Geography, Simon Fraser University

**STUDY DESIGN**

- 6 step analysis process: (1) summarize past events; (2) contextualize; (3) identify relevant concerns; (4) determine policies; (5) identify outcomes; and (6) identify future threats and opportunities
- review of grey literature documents identified from strategic searches and through key informants
- key informant interviews (n=7) conducted with people who have significant palliative care expertise and/or knowledge in BC
- review of legislative Hansard files from 1970s onward, looking for mentions of palliative care
- keyword search of BC newspapers for articles featuring stories about, or of relevance to, palliative care

**OVERVIEW**

In order to effectively address current health care challenges and operationalize a sustainable system it is useful to look back on how we have ended up in our current state of service delivery. An approach to doing this is to conduct an historical review of policy and practice. In this poster we present such a review specific to palliative care in British Columbia (BC), highlighting a limited number of key events. In critically reflecting on this timeline it is apparent that both macro-scale events (e.g., the shift from care in institutional settings to community settings) and micro-scale happenings (e.g., the opening/closing of particular hospice sites) have gendered implications for both those who give and receive care. We interrupt the linear flow of the timeline we have developed by inserting critical reflections about the implications of key happenings and events identified for women's paid and unpaid caregiving work at end-of-life.

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### BRITISH COLUMBIA'S PALLIATIVE CARE POLICY & PRACTICE TIMELINE

Year	Event	Gendered Implication (from sticky notes)
1978	Victoria & Vancouver Hospices Open	Until the late 1970s it was understood, at least by politicians, that palliative care was being provided in the home. The underlying implication is that the job security of care given primarily by women in the home space was eroded.
1984	BC Hospice Palliative Care Association Incorporated	Neoliberal restructuring of health care in the 1980s led to changes such as the ending of projects like building outcomes which many palliative care workers – most of whom were women – was eroded.
1995	Canadian Hospice Palliative Care Association meeting held in Vancouver	The establishment of these health authorities is important as it allows for the possibility of creating care initiatives that meet the needs of specific local groups (e.g., rural women, female immigrants, First Nations women etc.)
1995	Camel Place opens as North America's First Free Standing Children's Hospice	This is a foundational document for contemporary palliative care across Canada. Though offering a critical discussion about the role of gender as a key concept, it is variable for how palliative care is delivered and received.
1995	UBC Division of Palliative Care Founded (in Department of Family Practice)	Though identified as an important BC institution by sticky notes informed by key informants, critics of this program discuss changes women in most its eligibility criteria.
1995	Committee on Palliative Care Drugs for Patients at Home	Provincial legislation amended to recognize federal Compassionate Care Benefit program
1995	BC Cancer Association Pain & Symptom Management/Palliative Care Program Begins	Provincial legislation amended to recognize federal Compassionate Care Benefit program
2000	Learning Centre for Palliative Care Opened	Provincial legislation amended to recognize federal Compassionate Care Benefit program
2000	Regional Health Authorities Established	Provincial legislation amended to recognize federal Compassionate Care Benefit program
2000	BC Palliative Care Benefits Program and Palliative Care Drug Program and Medical Supplies and Equipments Benefits is Implemented	Provincial legislation amended to recognize federal Compassionate Care Benefit program
2000	Pallium Project (Run by Health Canada) Host Regional Palliative Care Workshops	Provincial legislation amended to recognize federal Compassionate Care Benefit program
2000	BC NewsLine Establishment - Can Serve as First Responder for Palliative Care	Provincial legislation amended to recognize federal Compassionate Care Benefit program
2006	Provincial End of Life Framework Created by the BC Ministry of Health	Provincial legislation amended to recognize federal Compassionate Care Benefit program

**IMPLICATIONS**

- Growing expectations for informal (usually female) caregivers to provide more medical and high-tech care.
- The home is increasingly becoming a site of care, affecting both the quality of life of informal caregivers and the quality of death for those receiving palliative care.
- Shrinking family sizes are reducing the number of potential caregivers thus resulting in increasing burdens to a smaller number of women which may result in caregiver burnout.
- Neoliberal restructuring and health care reform have increased the workload of formal caregivers, including those in the voluntary sector resulting in a deteriorating quality of work life.
- Though considered a primary health care priority by the BC Ministry of Health, hospice and palliative care programs are being increasingly subsidized through private partnerships

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