

Journal of Rural and Community Development

Evolution of Palliative Care in Ontario: The Impact of Geography, Funding, and Advocacy

Authors: Lily DeMiglio, Sarah Dykeman, Allison Williams, & Mary Lou Kelley

Citation:

DeMiglio, L., Dykeman, S., Williams, A., & Kelley, M. L. (2012). Evolution of palliative care in Ontario: The impact of geography, funding, and advocacy. *Journal of Rural and Community Development*, 7(4), 109-121.

Publisher:

Rural Development Institute, Brandon University.

Editor:

Dr. Doug Ramsey



**BRANDON
UNIVERSITY**
Founded 1899



Open Access Policy:

This journal provides open access to all of its content on the principle that making research freely available to the public supports a greater global exchange of knowledge. Such access is associated with increased readership and increased citation of an author's work.

Evolution of Palliative Care in Ontario: The Impact of Geography, Funding, and Advocacy

Lily DeMiglio

School of Geography & Earth Sciences
McMaster University
Hamilton, Ontario, Canada
demigllf@mcmaster.ca

Sarah Dykeman

School of Nursing
Trent University
Peterborough, Ontario, Canada
sadykeman@trentu.ca

Allison Williams

School of Geography and Earth Sciences, McMaster University
Hamilton, Ontario, Canada
awill@univmail.cis.mcmaster.ca

Mary Lou Kelley

School of Social Work
Centre for Education and Research on Aging and Health
Lakehead University
Thunder Bay, Ontario, Canada
mkelley@lsu.edu

Abstract

Despite the growing interest in and awareness of palliative care in Ontario, its evolution has not yet been described or explained. The purpose of this study was to examine the evolution of palliative care in the province of Ontario, with a large rural representation, in both area and impending need for palliative care. Academic and grey literatures were reviewed to synthesize a provincial timeline of key developmental milestones. Interviews (n=7) were conducted with stakeholders to confirm the validity of the timeline produced. Three temporal periods comprising the past 30 years of palliative care evolution in Ontario were determined: (1) the 1980s: the foundational years; (2) the 1990s: increased government involvement, and; (3) 2000+: stakeholders working together. Thematic analysis of interview transcripts revealed three emergent themes consistent throughout the three temporal periods: the impact of geography, funding, and advocacy on the development of palliative care in Ontario. These results can be useful in illustrating what facilitates and constrains the development of quality palliative care service delivery in other geographies, whether provincial, regional or national.

Keywords: palliative care, developmental milestones, geography, funding, advocacy

1.0 Introduction

Ontario is home to over 13 million residents which represents approximately 40% of Canada's population. Most Ontarians, however, live in or around urban areas as the majority of the province's land area is sparsely populated. About 85% of Ontarians live in urban settings, with 15% living in rural areas (Statistics Canada, 2009). Amidst changes in the delivery of primary care, the development of home care, changes in rates of hospitalization, and access to pharmaceutical support in the community, there have been a number of structural changes in the administration of health services. As one of the last provinces in Canada to regionalize, the province of Ontario was divided into fourteen Local Health Integration Networks in 2006. Local Health Integration Networks are responsible for planning health services in their jurisdiction (LHINs, 2006); the two in Northern Ontario serve the largest areas due to low population densities. The vast distances between population clusters in these areas makes delivering healthcare services in rural Ontario, including palliative care, a significant challenge for health policy makers, program planners, as well as front-line providers. As a result, much of the progress and program innovation specific to palliative care is most often situated in the urbanized southern region of Ontario (e.g. Kelley, 2007; Williams, 1996; Williams et al., 2010).

Although there are pockets of palliative care excellence in rural Ontario (Howell et al., 2011; Marshall et al., 2008), there is a general lack of healthcare services, providers, and palliative care education and training that limit the quality and extent of palliative care provided to dying people in northern and rural communities (Kelley, Sletmoen, Williams, Nadin, & Puiras, 2012). This inequity is accentuated by pockets of palliative care excellence being developed in urban areas, such as Hamilton, Kingston and Ottawa; local physician champions whom are often attached to teaching hospitals, have capitalized on the opportunity to build palliative care programs given their access to hospital and educational resources (e.g. Critchley, Lohfeld, McIntyre, & Reyno, 2002; Gaudette et al., 2002). There is ample evidence underlining the need to find ways to improve access to, and provision of, palliative care services in rural areas (Crooks & Schuurman, 2008). According to Crooks and Shuurman (2008), in Canada, rural palliative care seems to have fallen by the wayside for both researchers and decision-makers. They state:

Our concern is that those “in the trenches” providing front-line health services to residents of rural communities are highly aware of the pressing need to address this service gap, while, at the same time, this issue has yet to make it onto the agendas of most health care researchers and policy-makers (p. 139).

While research specific to rural palliative care is limited (Robinson et al., 2009), there is also a lack of research addressing the needs of Aboriginal peoples. In rural First Nations communities, many which are located in rural and isolated northern geographies, the lack of resources is complicated by language and cultural barriers (Prince & Kelley, 2010) and jurisdictional issues between the provincial and federal governments (see Marchildon, 2005).

The research presented in this paper was a secondary analysis of data from a larger research project, whereby Ontario was one of seven case study provinces sampled

and comparatively analysed (Williams et al., 2010). Provinces across Canada were strategically selected to represent the diversity of the nation, for the purpose of understanding the evolution of palliative care across Canada. The objective of this study was to describe the development of palliative care solely in the province of Ontario, and in so doing, demonstrate the factors that have impacted its evolution. Given the limited documentation available, together with a lack of available archival research, this paper attempts to provide a broad overview of what have been determined to be the three major time periods within the evolution of palliative care in the province. Further, we argue that geography, funding, and advocacy have had a substantial impact on the processes at play.

As the methodology is discussed in greater detail by Williams and colleagues (2010), only the basic steps are reviewed herein. The study took place between 2006 and 2010, following ethics clearance from McMaster University in Hamilton, Ontario. A review of the non-academic literature was undertaken to generate a draft policy timeline. Multiple sources of data were used to further elaborate on the timeline, including government and non-governmental reports, health reform papers, press releases, web resources, and academic literature.

The draft timeline was then reviewed and edited by Ontario-based stakeholders ($n=7$) who had been identified as key knowledge holders with respect to Ontario palliative care, both currently and historically. Stakeholders were selected due to their: (1) consistent representation in the palliative care literature and in media, and/or; (2) through personal recommendation by researchers and decision-makers, and/or; (3) through snowball sampling. The stakeholders came from a variety of settings, ranging from palliative care health providers, decision makers, and advocates (see Table 1 for key-informant characteristics).

Table 1: *Key-informant characteristics*

Key-informant	Professional background	Gender	Geographic representation	Age (years)	Experience in palliative care (years)
1	Advocacy	Female	Rural/urban	>40	>10
2	Government	Female	Rural/urban	>40	Unknown
3	Nursing & Advocacy	Female	Rural/northern	63	13
4	Nursing & Advocacy	Male	Rural/Urban	>40	15-20
5	Government	Female	Rural/Urban	52	16
6	Nursing	Female	Urban	42	20
7	Medicine & Advocacy	Male	Urban	63	34

Face-to-face interviews were conducted with stakeholders to receive feedback on the timeline created by the documentary analysis. After discussing any suggested edits, the stakeholders were further probed about palliative care policy events, turning points, as well as key challenges and successes. Interviews were semi-structured, audio-taped and transcribed verbatim. Analysis involved inductively generating themes from the data (Burnard, 1991) which were crosschecked for validation by members of the research team. Themes were then grouped into three

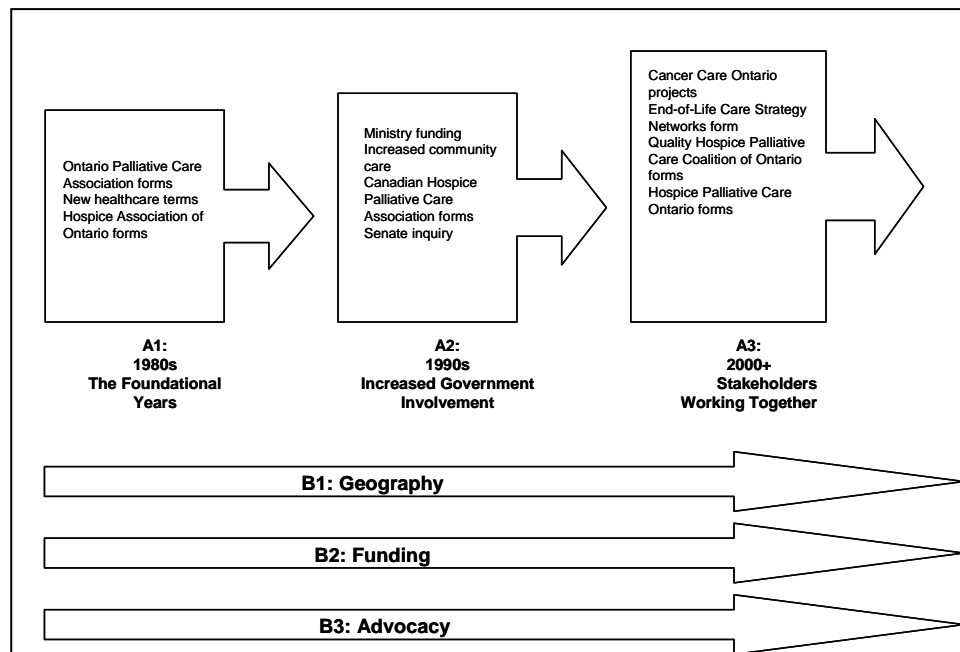
categories based on their common attributes and these three categories were consistent in each temporal period.

To gather more input, the study was presented at a provincial hospice palliative care conference in 2010. Confirming feedback from multiple audience members (frontline palliative care providers and decision makers) helped to verify the findings.

2.0 Results

Three distinct temporal periods in the evolution of palliative care emerged in the analysis: (A1) the 1980s: the foundational years; (A2) the 1990s: increased government involvement, and; (A3) 2000+: stakeholders working together. Thematic analysis of interview transcripts further revealed three emergent themes impacting on the development of palliative care in Ontario during each of the temporal periods: (B1) geography, (B2) funding, and (B3) advocacy. In what follows, each of the three time periods is presented, followed by a discussion of the three thematic results.

Figure 1. The three temporal periods with significant events and emergent thematic findings that shaped palliative care in Ontario.



A1. The 1980s: The Foundational Years

The term “palliative care¹” was coined by Dr. Balfour Mount, a cancer surgeon turned palliative care specialist, in Montreal Quebec in the early to mid 1970s (Saunders, 2000). According to a stakeholder, it was Dr. Mount’s advocacy work that prompted health professionals in southern Ontario to inventory the state of palliative care in the province and join forces for the purpose of advancing the discipline. Although Ontario lagged behind other provinces in palliative care development, the 1980s brought with it a decade of laying the groundwork for palliative care in Ontario. For example, there was a paradigm shift in the Canadian healthcare system as a whole. According to the Canadian

¹ It should be noted that the term “palliative care” is used interchangeably with “hospice palliative care” in Ontario.

Hospice Palliative Care Association, the healthcare system was adding new terms to its vocabulary in order to accommodate changes in the philosophy of care. New terms, such as “chronic”, “geriatric” and “palliative” were being used to describe the trajectory of a patient’s life-course (CHPCA, 2010). By the end of the 1980s, two provincial organizations existed – the Ontario Palliative Care Association and the Hospice Association of Ontario. Ontario was the only province to have two provincial organizations. The two southern Ontario-based organizations co-existed in the palliative care movement, both representing different memberships and foci as a means of addressing the needs of their membership. The Hospice Association of Ontario was considered as being more directly associated with residential hospice organizations while the Ontario Palliative Care Association had a similar but broader scope, representing providers working with dying individuals in various sectors and settings.

A2. The 1990s: Increased Government Involvement

As demonstrated in the timeline, few palliative care milestones occurred 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) provided funding for the purpose of increasing palliative care capacity in community services as opposed to hospitals. Separate initiatives that were developed through the funding included: 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 (Williams et al., 2002). These educational activities and supports coincided with major healthcare reform in Ontario in the mid-1990s, with a move away from institutional care to community-based care. These initiatives, which continue today, have been extremely valuable in improving capacity in palliative care in many areas of the province. However, these initiatives were not closely coordinated or distributed across the province, had limited funding and were not supported by health system reforms that would enhance their ability to improve palliative care delivery across the province. Therefore, while the majority of the programs still exist, the lack of dedicated funding led to the collapse or erosion in some communities.

In 1995 Community Care Access Centers were developed; these one-stop service centres enforced the momentum towards delivering care within the community and increasing opportunities for patients to remain at home even at the end of life. 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 (Sinclair, Rochon, & Kilbertus, 1998). Ultimately, it was through this shift that greater emphasis was placed on developing strong community and home palliative care programs.

The aforementioned 1992 funding from the Ministry of Health allowed for increased efforts to address fundamental rural health delivery challenges of access and quality, specifically for palliative care services. For example, it enabled the first interprofessional regional palliative care education to be developed and implemented with community providers and in long term care homes in northwestern Ontario (Habjan, Kortés-Miller, Kelley, Sullivan, & Pisco, 2012; Kortés-Miller, Habjan, Kelley, & Fortier, 2007). Stakeholders identified this funding as the first dedicated effort addressing palliative care in rural Ontario, whereas urban palliative care initiatives had received resources and support in prior years. This illustrates that rural Ontario lagged behind the rest of the province

by almost two decades, given that the developments made in the first period reviewed above all took place in the well-serviced, mainly urban, south. As a stakeholder confirmed, “*rural care is like a big black hole. It really is*”.

Ongoing events at the national level included the establishment of the Canadian Palliative Care Foundation, formed in 1991; the first office opened in 1994 (renamed as the Canadian Hospice Palliative Care Association in 2001). Public consultations into euthanasia were being made in the early 1990s and an instrumental national report with respect to palliative care in Canada was put forth in the 1995: *The Senate Committee Report on Life and Death*, led by Senator Sharon Carstairs, the former Federal Minister with Special Responsibility for Palliative Care (Senate of Canada, 1995).

Throughout the 1990s, palliative care in Ontario was characterized by increased government involvement at both the provincial and national levels. The 1992 dedicated palliative care funding and major restructuring of the healthcare system across the province had an effect on palliative care delivery in both urban and rural areas. In addition, the level of activity increased substantially at the federal level helped to generate advocacy for palliative care across the province.

A3. 2000 Onwards: Stakeholders Working Together

Despite the lack of palliative care progress in the early to mid 1990s, major headway was made by Cancer Care Ontario and various other stakeholders beginning in the late 1990s, specifically with the development of the Palliative Care Integration Project (Dudgeon et al., 2007). This project is a palliative care intervention that promotes common assessment and procedures. The success of a smaller project in southeastern Ontario led to the further development and implementation of the Provincial Palliative Care Integration Project in 2006 – a joint effort between the Ministry of Health and Long-Term Care and Cancer Care Ontario across the province of Ontario. It should also be noted that in 2004, Cancer Care Ontario identified palliative care as a priority area for the first time, channelling increased human and financial resources into the care population. One stakeholder explained “*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*”. The support for palliative care from Cancer Care Ontario was viewed as instrumental to the growing acceptance of palliative care across the province.

In 2005, Ontario announced the *End-of-Life Care Strategy* (Ministry of Health and Long-Term Care, 2005), improving access to home and community palliative care services. This strategy was a three-year \$115.5 million investment that targeted specific areas, including home care nursing and personal support services, residential hospices and volunteers, and the establishment of 14 Hospice Palliative Care Networks (one in each of the Local Health Integration Networks). Originally, the Hospice Palliative Care Networks were implemented around District Health Council boundaries in 2005 and later aligned and amalgamated to fit the new Local Health Integration Network boundaries in 2007. A stakeholder described the Hospice Palliative Care Networks as “*... 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 [Hospice Palliative Care] Networks and the possibilities that lie within those, I see great hope*”.

The significance of this strategy was enthusiastically discussed by one stakeholder: “*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*”. However, the provincial *End-of-Life Care Strategy* was time-limited from 2005 to 2008. Given that the funding period has expired, decisions to continue funding palliative care is now at the discretion of the Local Health Integration Networks (Seow, King, & Vaitonis, 2008). Funding is annualized and remains within each area to support integrated palliative care planning (i.e., the Networks). It is also important to recognize that the effectiveness of Hospice Palliative Care Networks is currently being evaluated due to their recent implementation (Seow et al., 2008). As exemplified by the stakeholder quoted above, while there is optimism, an evaluation of the Hospice Palliative Care Networks still needs to happen.

An increase in the Hospice Association of Ontario’s membership in 2008 affirmed a growing response and acceptance of palliative care at the community level, stemming in part from the provincial focus on palliative care through the *End-of-Life Care Strategy*. Another significant step in the palliative care movement occurred when the Hospice Association of Ontario and Ontario Palliative Care Association collaborated to host the annual provincial palliative care conference in 2009. The two organizations have since merged and now operate as Hospice Palliative Care Ontario (HPCO, 2012). The impetus behind the merger was strategic and based on the need for a strong, unified “voice” which could be better achieved through one association. Also in 2009, a number of stakeholder groups, including the provincial Hospice Palliative Care Networks, the Ontario College of Family Physicians, the Hospice Association of Ontario and Ontario Palliative Care Association, and Cancer Care Ontario, joined together to form a provincial palliative care consortium at the Palliative Care Provincial Think Tank. This collaboration now referred to as the *Quality Hospice Palliative Care Coalition of Ontario* shows that multiple stakeholders have begun to work together towards a common goal for advancing and integrating palliative care across the province.

Even though a comparatively greater degree of collaboration has occurred across stakeholder groups, additional challenges in moving forward have been recognized. One often cited is the lack of clarity in the language and definition of palliative care (e.g., CHPCA, 2010). Terms such as *palliative care*, *hospice care*, *end-of-life care* and *supportive care* are all used to describe holistic comfort-oriented care for people when there is an expected death. As described by one stakeholder, “...in the palliative care community, there have been major discrepancies in how people communicate the so-called common language of palliative care”.

Rural palliative care also received some increased financial assistance during this time period. *Pallium* was an educational initiative that ran from 2004 to 2006 and was funded through the federal Primary Healthcare Transition Fund (Aherne & Pereira, 2005). While primarily focused on the western provinces, in some areas of Ontario this initiative enhanced resources for rural practitioners in palliative care, providing increased training and education in the development of palliative care knowledge. Further, in 2006, provincial and federal governments allocated development funding for the construction of three northern residential hospices in Sudbury, Sault Ste. Marie and Thunder Bay. However, the Thunder Bay hospice

was not able to be constructed due to lack of commitment for the required ongoing operating funds.

Also during this time period, the aforementioned 1995 senate report was updated with the release of three additional reports: (1) *Quality EoL Care: The Right of Every Canadian*; (2) *Still Not There: Quality EoL Care – A Progress Report* and; (3) *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*. Many other key federal events and reports were produced (for a detailed list, see Williams et al., 2010).

Similar to the influence Senator Sharon Carstairs has on palliative care nationally (see Carstairs, 2010), palliative care development in Ontario would not have been possible without the efforts of many organizations and individuals. Stakeholders repeatedly noted both the importance of formal and informal organizations, including their dedicated volunteers and advocates: “*Hospice palliative care has always been a grassroots movement, that is, the people who are at the frontline 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*”. Individual advocates were identified at both the community and provincial level including healthcare providers, decision makers and volunteers. Specific to rural communities, these grassroots efforts are more central, and imperative than in urban areas; that is, if their efforts were nonexistent, palliative care would be compromised or nonexistent.

Although changes are slowly occurring across the system, Ontario has not been the pioneering province for change implementation. For example, new policies and procedures for paramedics and firefighters responding to expected home deaths have been established only recently (Verbeek & Sherwood, 2007), later than other provincial jurisdictions. These new policies and procedures have standardized ‘Do Not Resuscitate’ orders across the province, enabling paramedics and firefighters to honour the end-of-life preferences of those that die at home.

3.0 Emergent Thematic Findings

The stakeholder interviews provided insight into the factors that influenced the evolution of palliative care development in Ontario. Three temporal periods were conceptualized: (1) foundational events; (2) increased government involvement and; (3) stakeholders working together. Each temporal period had distinct features: however, consistent across these three time periods was the important influence of geography, governmental funding, and advocacy. These variables highlight the impact of place, resources, and people on palliative care.

B1. Geography

Rural geographies in Ontario encompass remote, northern, and isolated areas. Given the medically underserved history of rural Ontario (Anderson & Rosenberg, 1990; Williams, 1996; 2006; Williams & Cutchin, 2002), palliative care has been slow to develop when compared to the well-served, highly urbanized southern region of the province. This has resulted in rural Ontario having a relative lack of health care services, providers, and palliative care education and training that limit the quality and extent of palliative care that is accessible to dying people and their families. This contrasts with much of the southern and highly urbanized region of the province that benefits from being well-served and having access to teaching hospitals, specialized health care

professionals (e.g., Pong & Pitblado, 2005), current technology and a continuum of specialized services. This concentration of resources inevitably creates opportunities for development of palliative care specialization. On the other hand, community capacity building initiatives in rural Ontario have proven to provide basic and often innovative community-based palliative care programs (Kelley, 2007; Kelley, Williams, DeMiglio, & Mettam, 2011; Kelley, Sletmoen, Williams, Nadin, & Puiras, 2012); such initiatives build on the assets of rural culture and community orientation, including social cohesion and sense of community (Troughton, 1999), and are particularly necessary given the comparatively lower health status of rural populations (DesMeules et al., 2012). Recognizing that the geographical differences across the province are likely not going to change substantially over time, using what is available to local communities to create and grow locally-responsive palliative care programs is an effective and low-cost solution to the inequalities that exist in the availability, access and quality of palliative care services across place.

B2. Funding

The three time periods presented herein illustrate a number of shifts in government priorities and funding. Early in the 1990s, increased provincial funding suggested government's interest in preparing for what has been called the 'demographic tsunami' in death and dying. This was further confirmed in 2005, when the Ministry of Health and Long-Term Care announced the *End-of-Life Care Strategy*, together with the Hospice Palliative Care Networks. Shifts in government funding for primary care, chronic disease management and palliative care specifically have proven to affect the speed and intensity of progress. Although there have been many community-based initiatives that have received short-term, unsustainable funding for palliative care programs and services (e.g., recall the aforementioned Federal funding through Pallium), it will inevitably be government that will be tasked with funding palliative care services given that these services have been slow to evolve outside of insured hospital and physician provided care. Given the current fiscal restraints that governments are facing, this task will likely prove to be a challenge. The move to community care has tasked families, and specifically family caregivers, to learn, manage and provide palliative care in the home; focusing resources on family caregivers may prove to minimize caregiver burden, burnout and ultimately, place less pressure on the healthcare system.

B3. Advocacy

Over the course of the three periods presented above, the advocacy for palliative care has not waned. As a substantive area, palliative care continues to be a passion for visionaries, pioneers and champions who advocate for its ongoing development and sustainability across the health care system. Although it is impossible to acknowledge all individuals who have championed the cause in Ontario, many would recognize the names of individuals who have consistently contributed their expertise to palliative care research and public awareness. Certainly many members of the Hospice Palliative Care Ontario continue to move palliative care forward in the province, as does Cancer Care Ontario, the newly established Quality Hospice Palliative Care Coalition of Ontario, and on the community level, individuals working with the Hospice Palliative Care Networks.

4.0 Discussion and Conclusions

Despite our efforts, fragmented documentation, combined with the need to rely mostly on a limited number of stakeholder accounts, made the tracking of palliative care evolution a difficult endeavour. This limitation was addressed by cross-checking facts in the grey and academic literatures as well as through informal discussions with expert researchers, palliative care stakeholders and pioneers in palliative care. Although outside the parameter of this paper, the historical tracing of the developmental trajectory of palliative care across Canada and internationally would provide a more comprehensive context for understanding its development in Ontario.

The objective of this paper was to present the findings of a qualitative analysis of palliative care evolution in Ontario. Using information gathered from a documentary analysis, together with in-depth one-on-one interviews with a group of stakeholders, a timeline of key milestones in palliative care evolution in Ontario was developed. Three temporal periods comprising the past 30 years of palliative care evolution in Ontario were determined: (1) the 1980s: the foundational years; (2) the 1990s: increased government involvement, and; (3) 2000+: stakeholders working together. Thematic analysis of interview transcripts revealed three emergent themes consistent throughout the three temporal periods: the impact of geography, funding, and advocacy on the development of palliative care in Ontario. Despite shifts in government priorities and funding, advocacy for palliative care has not waned, although reducing the gap between palliative care in urban and rural Ontario continues to require ongoing efforts. Although our case study is specific to Ontario, other regions may benefit from examining the influence of geography, government resources, and advocacy in moving palliative care forward.

To test whether or not the thematic findings are unique or novel, or applied to other places (whether another Canadian provincial jurisdiction, or possibly another nation state), and/or specialties, researchers would need to conduct similar case study work in other places and within other specialties. Further research such as this would benefit our understanding of how specialized health services are shaped over space and time. This knowledge can benefit emerging specialties such as dementia care, cancer care and emergent human health resources, such as physician assisted care.

We trust that the results of this paper add value to the palliative care literature in Canada, and hope they can be useful in illustrating what impedes as well as advances the development of quality palliative service delivery in other geographies, whether provincial, regional or national. Given the vulnerability of palliative care, we need to better understand how to better develop it and sustain it. Further, there are no common approaches to or substantial integration of palliative care across hospital, hospice, long-term care and home care settings, which are the major sites of death. Palliative Care has the unique challenge of being mainly provided as a primary care service across multiple settings. Thus, for developmental changes to occur, multiple sectors and health care professionals need to be involved and cognizant of the influence of geography, funding and advocacy.

5.0 Acknowledgement

CIHR ICE grant HOA-80057 titled 'Timely Access and Seamless Transitions in Rural Palliative/End-of-Life Care' was funded through CIHR Institute of Cancer

Research and CIHR Institute of Health Services and Policy Research to A. Williams and D. Wilson (Co-PIs), and Co-Investigators: K. Brazil, D. Brooks, N. Chappell, W. Duggleby, R. Fainsinger, L. Fillion, D. Cloutier-Fisher, D. Goodridge, C. Justice, S. Kaasalainen, M.L. Kelley, K. Kovacs-Burns, M. MacLean, D. Marshall, V. Menec, J.L. Richards, C. Ross, A. Taniguchi, R. Thomas, C. Truman, and K. Willison.

6.0 References

- Aherne, M., & Pereira, J. (2005). A generative response to palliative service capacity in Canada. *Leadership in Health Services*, 18(1), iii-xxi.
- Anderson, M., & Rosenberg, M. W. (1990). Ontario's underserved area program revisited: an indirect analysis. *Social Science & Medicine*, 30(1), 35-44.
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nursing Education Today*, 11, 461-466.
- Carstairs, S. (2010). Raising the bar: a roadmap for the future of palliative care in Canada." Retrieved March 5, 2012, from http://www.virtualhospice.ca/Assets/Raising%20the%20Bar%20June%202010_Senator%20Sharon%20Carstairs_20100608160433.pdf
- CHPCA. (2010). The Canadian Hospice Palliative Care Association... A History. Retrieved March 5, 2012, from <http://www.chpca.net/History>
- Critchley, P. P., Lohfeld, L., McIntyre, P. & Reyno, L. (2002). The challenge of developing a regional palliative care data system: a tale of two cities. *Journal of Palliative Care*, 18(1), 7-14.
- Crooks, V. A., & Schuurman, N. (2008). Reminder: palliative care is a rural medicine issue. *Canadian Journal of Rural Medicine*, 13(3), 139-140.
- DesMeules, M., Pong, R. W., Read Guernsey, J., Wang, F., Luo, W., & Dressler, M. P. (2012). Rural health status and determinants in Canada. In J. C. Kulig & A. M. Williams (Eds.), *Health in Rural Canada* (pp. 23-43). Vancouver, BC: UBC Press.
- Dudgeon, D., Vaitonis, V., Seow, H., King, S., Angus, H., & Sawka, C. (2007). Ontario, Canada: using networks to integrate palliative care province-wide. *Journal of Pain and Symptom Management*, 33(5), 640-644.
- Gaudette, L. A., Lipskie, T., Allard, P., Fainsinger, R., Maxwell, D., & Harlos, M. (2002). Developing palliative care surveillance in Canada: results of a pilot study. *Journal of Palliative Care*, 18(4), 262-269.
- Habjan, S., Kortes-Miller, K., Kelley, M. L., Sullivan, H., & Pisco, L. (2012). Building capacity in rural health services: the effect of continuing education. In J. C. Kulig & A. M. Williams (Eds.), *Health in Rural Canada* (pp. 118-136). Vancouver, BC: UBC Press.
- Howell, D., Marshall, D., Brazil, K, Taniguchi, A., Howard, M., Foster, G., & Thabane, L. (2011). A shared care model pilot for palliative home care in a rural area: impact on symptoms, distress, and place of death. *Journal of Pain & Symptom Management*, 42, 60-75.

- HPCO. (2012). About HPCO. Retrieved March 5, 2012, from <http://hpcoco.ca/who-we-are/>
- Kelley, M. L. (2007). Developing rural communities' capacity for palliative care: a conceptual model. *Journal of Palliative Care*, 23(3), 143-153.
- Kelley, M. L., Sletmoen, W., Williams, A. M., Nadin, S., & Puiras, T. (2012). Integrating policy, research, and community development: a case study of developing rural palliative care. In J. C. Kulig & A. M. Williams (Eds.), *Health in Rural Canada* (pp. 219-238). Vancouver, BC: UBC Press.
- Kelley, M. L., Williams, A., DeMiglio, L., & Mettam, H. (2011). Developing rural palliative care: validating a conceptual model. *Rural and Remote Health*, 11 (online), 1717.
- Kortes-Miller, K., Habjan, S., Kelley, M. L., & Fortier, M. (2007). Development of a palliative care education program in rural long-term care facilities. *Journal of Palliative Care*, 23(3), 154-162.
- LHINs. (2006). Ontario's Local Health Integration Networks. Retrieved March 5, 2012, from <http://www.lhins.on.ca/home.aspx?LangType=4105>
- Marchildon, G. P. (2005). *Health Systems in Transition: Canada*. Toronto, ON: University of Toronto Press.
- Marshall, D., Howell D., Brazil K., Howard M., & Taniguchi, A. (2008). Enhancing family physician capacity to deliver quality palliative home care: an end-of-life, shared-care model. *Canadian Family Physician*, 54, 1703.e1-7.
- Ministry of Health and Long-Term Care. (2005, October 4). McGuinty government improving end-of-life care: strategy will enhance services in homes and hospices. Media release. Retrieved March 5, 2012, from http://www.health.gov.on.ca/english/media/news_releases/archives/nr_05/nr_100405.html
- Pong, R. J., & Pitblado, J. R. (2005). Geographic distribution of physicians in Canada: beyond how many and where. Ottawa: CIHI.
- Prince, H., & Kelley, M. L. (2010). An integrative framework for conducting palliative care research with First Nations communities. *Journal of Palliative Care*, 26(1), 47-53.
- Robinson, C. A., Pesut, B., Bottorff, J. L., Mowry, A., Broughton, S., & Fyles, G. (2009). Rural palliative care: a comprehensive review. *Journal of Palliative Medicine*, 12(3), 253-258.
- Saunders, C. (2000). The evolution of palliative care. *Patient Education and Counselling*, 41, 7-13.
- Senate of Canada. (1995). *Of Life and Death: Report of the Special Senate Committee on Euthanasia and Assisted Suicide*. Ottawa, ON: Minister of Supply and Services Canada.
- Seow, H., King, S., & Vaitonis, V. (2008). The impact of Ontario's End-of-Life Care Strategy on end-of-life care in the community. *Healthcare Quarterly*, 11(1), 56-62.

- Sinclair, D. G., Rochon, M., & Kilbertus, P. (1998). A status report on hospital restructuring in Ontario. *Hospital Quarterly*, 2(1), 57-60.
- Statistics Canada. (2009). Population urban and rural, by province and territory (Canada). Retrieved March 5, 2012, from <http://www40.statcan.ca/101/cst01/demo62a-eng.htm>
- Troughton, M. J. (1999). Redefining “rural” for the twenty-first century. In W. J. Ramp, J. Kulig, I Townshend, & V. McGowan (Eds.), *Health in Rural Settings: Context for Action* (pp. 21-38). Lethbridge, AB: University of Lethbridge.
- Verbeek, R., & Sherwood, C. (2007). End-of-life care in the home: how a new procedure for Ontario paramedics and firefighters may affect your patients and your practice. *Ontario Medical Review*, November, 39-43.
- Williams, A. (1996). The development of Ontario’s home care program: a critical geographical analysis. *Social Science & Medicine*, 42(6), 937-948.
- Williams, A. (2006). Restructuring home care in the 1990s: geographical differentiation in Ontario, Canada. *Health and Place*, 12(2), 222-238.
- Williams, A., & Cutchin, M. (2002). The rural context of health care provision. *Journal of Interprofessional Care*, 16(2), 107-115.
- Williams, A., Crooks, V. A., Whitfield, K., Kelley, M. L., Richards, J. L., DeMiglio, L., & Dykeman, S. (2010). Tracking the evolution of hospice palliative care in Canada: a comparative case study analysis of seven provinces. *BMC Health Services Research*, 10(147).
- Williams, A., Montelpare, W., Wilson, S., Cheng, S., Tremelling, K., & Wells, C. (2002). An assessment of the utility of formalized palliative care education: a Niagara case study. *Journal of Hospice and Palliative Nursing*, 42(2), 103-110.