

# Was the 5th International Public Health Palliative Care Conference 2017 Canada's tipping point? —a meeting report

Denise Marshall<sup>1</sup>, Kathy Kortés-Miller<sup>2</sup>

<sup>1</sup>Department of Family Medicine, Division of Palliative Care, McMaster University, Hamilton, Ontario, Canada; <sup>2</sup>School of Social Work, Lakehead University, Thunder Bay, Ontario, Canada

Correspondence to: Denise Marshall, MD, CCFP(PC), FCFP. Professor, Department of Family Medicine, Division of Palliative Care, McMaster University, Hamilton, Ontario, Canada. Email: marshald@mcmaster.ca.

Submitted Feb 27, 2018. Accepted for publication Mar 13, 2018.

doi: 10.21037/apm.2018.03.07

View this article at: <http://dx.doi.org/10.21037/apm.2018.03.07>

## Background

Canadians are living longer than they ever have before, but not necessarily better. It is projected that 3.3 million Canadians will be aged 80 or older by 2036. Yet only 13% have an advanced care plan prepared (1) which means too few Canadians are actively discussing end of life. Our national Globe and Mail health reporter Andre Picard has likened accessing palliative care in Canada to winning the postal code lottery (personal correspondence Andre Picard 2016). Yet there appears to be a new energy and a shift in focus in Canada—perhaps even a reclaiming of the dying process, as more Canadians “re-member” (2) that dying as a social, familial and community event. No doubt national readiness for this shift has been percolating for decades, thanks to the Canadian legacy of spawning and leading the development of palliative care as a vital component of healthcare (3). Perhaps it's been given a further nudge with the inherent tensions created with legislation for Medical Assistance in Dying (MAID) introduced across Canada in June 2016 (4). Regardless, dying and “dying well” has increasingly crept into the psyche of Canadians in new and bold ways. Canadian society is recognizing the need to prioritize learning and talking about end-of-life.

This past September 2017, Ottawa, Canada was host to the 5th International Public Health Palliative Care Conference (PHPC17). This event was organized and spearheaded by the Canadian Hospice Palliative Care Association and well partnered with Public Health Palliative Care International, Pallium Canada and McMaster University. The conference organizers recognized opportunity for the conference to advance issues globally

and for Canada, the potential to reach a “tipping point”. Malcolm Gladwell defines a tipping point as: “*the moment of critical mass, the threshold, the boiling point*” (5). This appears to be unfolding in Canada right now, as compassionate communities and palliative care public health initiatives are bursting forth across our country. The opportunity to host PHPC17 was a catalyst to this.

## Methods

### *The conference: PHPC17*

Over a 4-day period in September, over 300 delegates from 33 countries descended upon Ottawa Ontario, Canada, the nation's capital to learn from, with and about exciting and groundbreaking approaches to palliative care as a public health issue. The location of the conference, in the city that hosted the development of the World Health Organizations Ottawa Charter for Public Health in November of 1986, was intentional. The timing of the conference in Canada during the midst of the nation's 150 celebration of confederation was fortuitous, as it highlighted Canada as a community-oriented country on which the landscape of how its citizens are dying is changing and growing with compassion and care. Building on the successful growth of numbers and countries represented at the 4th International conference held in Bristol UK in 2015, PHPC17 set a goal of enhancing accessibility of the conference for delegates from low and middle-income countries (LMIC). International Association for Hospice and Palliative Care (IAHPC) provided traveling scholarships to 12 healthcare professionals to attend the conference. These scholarship

recipients joined us from four continents coming from 11 countries: Bangladesh, Chile, China, India, Iraq, Nigeria, Rwanda, Tanzania, the United Kingdom, Ukraine, and Zimbabwe. In total there were participants from 16 different LMICs who attended the conference.

In addition to healthcare clinicians, educators, researchers, administrators and policy makers attending, this conference also welcomed members of the wider community and specifically the citizens group called Compassionate Ottawa. Compassionate Ottawa is a volunteer-facilitated, community-led initiative working to improve quality of life until the end of life (6). A highlight of this forum was an address by one of Canada's most iconic palliative care leaders and activists, Senator Sharon Carstairs, who examined palliative care from a public health perspective and highlighted the activism of grassroots Canadians.

The conference was organized around the five overarching tenets of the WHO Ottawa Charter for Public Health that also served as the guiding themes for the five plenary presentations:

- ❖ Building public policies that support health;
- ❖ Creating participatory community partnerships;
- ❖ Strengthening sustainable community partnerships;
- ❖ Evaluation and performance;
- ❖ Reorienting/engaging environments to be responsive to death dying loss and bereavement.

The 437 conference participants took advantage of the five plenaries from leaders around the world and over 50 workshops and presentations highlighting the groundswell and new research moving the public health palliative care movement forward. In addition, there were 40 interactive poster presentations, eight fireside chats on cutting edge initiatives and five Canadian toques circulating to stimulate discussion and networking. Building off of the enhanced social media presence at the conference in Bristol, there was a large Twitter presence at the conference with over 2,500 tweets.

## Results

### *Emergent themes*

As plenaries, workshops, and facilitated poster presentations were presented, it became evident that some consistent themes were emerging. These themes also formed the conversation topics happening during the informal “fireside chat” segment of the conference. We would like to highlight

three themes that we observed emerging over the course of the conference; dying matters; the need for buy-in; and shifting our focus. All three have relevance for Canada's future momentum.

### *Dying matters*

Not surprising for an international palliative care conference, “dying matters” emerged as a theme. However, this was articulated with a crisp and clear focus on the individual experience of dying as opposed to the role that dying plays within our healthcare system. In the opening plenary panel, Canadian Dr. Alex Jahad gave voice to this when he stated “*My dying should be the most important event of my life*”. Dr. Julien Abel from the United Kingdom followed up on this in his plenary when he challenged participants “*to not leave death to the experts*”. Rather, he invited participants to think of it as a social event supported primarily by communities and community relationships as opposed to healthcare professionals and formalized systems. This was further echoed by Dr. Christian Nzitimara from Rwanda who introduced participants to UBUNTU, an African term used to describe the belief in a universal bond of sharing that connects all humanity. Dr. Nzitimara shared that “*When you are well, you belong to yourself. When you are sick you belong to your family*”. This was subsequently summarized by the architect of Health Promoting Palliative Care and Compassionate Communities Dr. Alan Kellehear when he said “*We are involved in a progressive and civic movement. It is the future of end-of-life care*”.

### *The buy-in*

Despite the alignment of “dying matters” as a core emergent theme amongst speakers and presenters, a second and seemingly more urgent theme emerged. Coined as “the buy-in”, this theme spoke to the current reality that an all-citizens or all-sector collective agreement that “dying matters” was elusive across many jurisdictions in the world. Canadian physician and public health expert Dr. Ross Upshur recognized this challenge at a macro level and posited “*How can we make the integration of palliative care and public health be seen as a public health achievement?*” Jessie Williams, executive officer of The Groundswell Project from Australia colourfully suggested that “*if you can blend into new environments and not create panic, you can change s\*\*\* up!*” Dr. Zipporah Ali from Kenya stated the need for developing community connections was the absolute priority. She summarized the need for widespread buy in as “*If it doesn't happen in the community it doesn't happen*”.

### *Shifting Our Focus*

When speaking of paradigm shifts, Chief Executive of St Nicholas Hospice Care, Barbara Gale from the UK frankly challenged: “*We have put too many of our eggs in the healthcare basket and left the community behind. We need to think like social activists*”. Dr. Julian Abel provided a concrete example of what this could look like when he encouraged participants to rethink their approach to advance care planning and consider it as a community led initiative, not merely healthcare driven. He repeatedly identified the need to shift and act beyond the rhetoric of “patient-centred care” to true networks where care can where we live and die and in the context of people around us—our communities. Dr. Kellehear’s phrase that “*a healthcare provider is a poor excuse for a friend*” was positioned and referenced many times as a mantra for this new focus. And while knowledge about a palliative approach to care for healthcare providers was seen as important, it was not discussed as the key driver of the public health palliative care approach. As Julian Abel argued “*Pain management is the easy part. Communities of support is the most meaningful. It is time to reframe*”.

### **Taking responsibility**

As these three themes emerged throughout the conference, delegates began discussing the white elephant of responsibility. Who exactly, should be responsible to move this forward? PHPC17 highlighted that community engagement and education is required at all systems levels and messages were consistent with those from the World Health Organization: “*For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community*” (7). Dr. Julien Abel stated that as a priority, our organizations need community developers and those skilled as “Health Connectors”. There was widespread endorsement that leadership and facilitation is now required from both traditional palliative care sectors and public health communities. Abel warned though, that as per PHPC founders Bruce Rumbold’s previously articulated caution, all aspects of the Ottawa Charter need action, and though tempting, we should not “cherry pick” the Ottawa Charter in pursuit of a public health approach to palliative care at this time. Due diligence and rigorous implementation were advised. “Imaginative collaboration” was referenced as an opportunity for palliative care providers, healthcare clinicians, educators and researchers to co-imagine and

### **Marshall and Kortes-Miller. Was PHPC17 Canada’s tipping point?**

co-create community driven initiatives that can be self-supported and sustainable as they move towards achieving the Compassionate Cities Charter (8). A number of delegates spoke of their new-found realization that culture shift can and should drive policy change.

### **Perceptible shifts in the Canadian psyche**

For the Canadian organizers of this international conference, one of the goals of hosting was to foster shifts in our own Canadian psyche pertaining to PHPC through the influence and stimulus of the conference on the substantive number of national delegates and community members who attended. The delegate feedback via the conference evaluation process suggests that may have been achieved. One evaluation summarized this well: “*I believe the ripple effect will turn into a roaring stream of valuable community engagement across the world. The examples of what others are doing, how it all actually works specifically in the great variety of communities is very important as examples for our country. I couldn’t be more inspired!*” In particular, commentary provided by delegates suggest five areas with potential to help “tip” the shift in Canada.

### *Social mentorship through community development and engagement*

Canadians pride themselves on their capacity to grow, support and nurture a community literally from the ground up. Delegates had abundant opportunity to awaken to the social imperative of mentorship and capacity building around a “good death” in their communities. Laying down the gauntlet on this was the executive director of the Groundswell Project, Jessie Williams from Australia. Simply put, Jessie’s message of mentorship to Canadians was “*we don’t normalize, we socialize*”. Canadian delegates reported that application of this kind of social mentorship resonated well with them and was a good fit for community engagement in palliative and end-of-life care in Canada.

### *Accountability and evaluation*

A challenge now for jurisdictions like Canada with historic strengths in community development, is to contribute towards systems accountability and robust PHPC evaluation on such initiatives. In their keynote address, leading public health researchers Dr. Joachim Cohen from Belgium and Dr. Libby Salnow from the UK outlined that both

qualitative and quantitative research methodologies have a role here in capturing the experiences of communities developing their capacity to care for their own at the end of life. Canadian delegates were challenged to consider how best to implement evaluation strategies to communicate the impact and benefits of their community development initiatives.

PhD candidate and co-founder of the Australian Groundswell Project, Kerrie Noonan introduced delegates to the development of a death literacy index (DLI). Kerrie challenged Canadians to use a validated tool such as the DLI as an objective measure of knowledge and wisdom gained by people caring for the dying. She further prompted Canadian delegates to pay attention to the death literacy rates in our country as a means to drive community focused and sustainable end of life systems and social support.

### *First nations experiences as exemplars*

The 5th international conference featured Canadian first nations initiatives as exemplars of communities developing capacity to care for their own at the end of life. Many first nations people in Canada want the opportunity to die in the communities where they have lived all of their lives. Conference attendees heard however, that people in first nations communities have limited access to culturally relevant and formalized palliative care programs. Despite this lack of government funded systems and resources, a number of presentations demonstrated the robust ability of first nations people to use their traditional knowledge to provide care at the end of life. Participants were challenged to learn from the community development experiences in these first nations and consider heightened mobilization efforts in their own community. There was a sense amongst delegates that the first nations experiences were key to their understanding about how to shift towards a capacity building approach in communities that could strengthen natural helping networks. The powerful impact of this message resonated for both Canadian and international delegates especially those who tended to rely on formalized care systems to lead.

### *Rural and remote*

Despite (or perhaps because of) the Canadian awareness of our “postal code lottery” access to palliative care, Canadian delegates at this conference seemed particularly impacted by the ability of people and programs in LMIC to overcome similar issues of rurality and remoteness with few formalized

resources. In particular, presentations from Kenya, Rwanda, and South America created a sense of worldwide solidarity around provision of community driven care in sparse locations. There was considerable reciprocity with sharing, story-telling and connecting amongst delegates who represented rural and remote places across the globe. Adding to this was the powerful research of New Zealander Dr. Merryn Gott who shared digital stories presenting the perspectives of Maori carers caregiving for their loved ones in rural communities at the end-of-life.

## **Conclusions**

The 3rd International Public Health and Palliative Care conference, Limerick Ireland 2013, was an entry point for Canada into the international PHPC dialogue. The 4th International Public Health and Palliative Care Conference Bristol UK 2015 created momentum and confidence for Canada. The 5th International Public Health and Palliative Care conference has now offered itself to Canada as a tipping point catalyst for a national focus on public health palliative care, and adoption of the global Compassionate Communities movement. The next 24 months prior to the 6th international meeting in Sydney Australia in 2019 will be telling for Canada and likely for many other countries. Will Compassionate Communities projects thrive across Canada? Will formative advance care planning discussions occur regularly as part of community network initiatives? We will see the emergence of health connector and community developer roles in our palliative care organizations?

Canadian delegates at PHPC17 reported that participating in this event created an awareness that Canada is indeed at a tipping point with increasing clarity about next steps. Armed with new insights from international experiences shared in Ottawa at PHPC17 these delegates saw themselves as the “critical mass” needed to tip and shift Canada towards truly realizing a “good death for all”.

## **Acknowledgements**

Thanks to all the inspiring leaders who spoke at PHPC17, and to the Canadian Hospice Palliative Care Association for supporting the conference.

## **Footnote**

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

## References

1. Canadian Hospice Palliative Care Association. Ottawa: CHPCA Fact Sheet Available online: [http://www.chpca.net/media/557647/new\\_fact\\_sheet\\_hpc\\_in\\_canada-summer2017-final-en.pdf](http://www.chpca.net/media/557647/new_fact_sheet_hpc_in_canada-summer2017-final-en.pdf)
2. Palmer PJ. *The Courage to Teach: Exploring the Inner Landscape of a Teacher's Life*. San Francisco: John Wiley & Sons Inc., 1998:20.
3. Westley F, Zimmerman B, Patton M. *Getting to Maybe: How the World Is Changed*. Toronto: Random House of Canada Limited, 2007:119.
4. *Carter v. Canada: The Supreme Court of Canada's Decision on Assisted Dying*. Available online: <http://lop.parl.ca/content/lop/ResearchPublications/2015-47-e.html>
5. Gladwell M. *The Tipping Point: How Little Things Can Make a Big Difference*. Boston: Little, Brown and Company, 2002:13.
6. Compassionate Ottawa. Ottawa: About us. Available online: <http://compassionateottawa.ca/about-us/>
7. Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. *J Pain Symptom Manage* 2007;33:486-93.
8. Public Health Palliative Care International. *Compassionate Communities Charter*, PHPCI website. Available online: <http://www.phpci.info/tools/>

**Cite this article as:** Marshall D, Kortes-Miller K. Was the 5th International Public Health Palliative Care Conference 2017 Canada's tipping point? —a meeting report. *Ann Palliat Med* 2018;7(Suppl 2):S130-S134. doi: 10.21037/apm.2018.03.07