

Canadian Society of Palliative Care Physicians – Response to “The Making of a Myth: Unreliable Data on Access to Palliative Care in Canada”

Regarding the commentary “The Making of a Myth: Unreliable Data on Access to Palliative Care in Canada,” **the Board of The Canadian Society of Palliative Care Physicians agrees that** “We lack up to date, reliable data on access to palliative care across Canada that includes palliative care delivered outside of acute care hospitals. Until this data is gathered, we can only say that access to palliative care in Canada varies wildly and research is desperately needed if our policy-making on assisted dying is going to rest in any legitimate way on claims about the availability of palliative care.”

We have, however, grave concerns about the commentary’s implicit assumption that access is possibly not a problem.

The data claiming 16-30% access was limited and it is old. We agree that access has improved in the 11 years since the original data was obtained in the CIHI report from 2003-04; however, we know through our on-the-ground experience that huge gaps still exist.

Even within provinces, access varies, as outlined in the 2014 Auditor General’s Report from Ontario <<http://www.auditor.on.ca>> – pp. 259-289). The report clearly

discusses the difficulties accessing end-of-life care services, and suggests that education standards are needed for physicians and nurses to help ensure proper patient care.

As stated in the commentary, basic Palliative Care competencies for all Canadian physicians were developed nationally in 2008 through the Educating Future Physicians in Palliative and End of Life Care (EFPPEC) project. Competencies for nursing and social work have also recently been developed. Unfortunately most physicians, nurses and social workers have received very little if any education in Palliative Care. The study, Undergraduate Training in Palliative Care in Canada in 2011, presented by Serge Daneault MD, PhD, FRCPC Soins palliatifs, Hôpital Notre Dame Centre Hospitalier de l’Université de Montréal, June 7, 2012, found that 10 of the 17 medical schools in Canada offered 10 hours or less of palliative medicine education in their undergraduate programs. Further research is required to assess this in more depth.

A 2014 Ipsos Reid Survey commissioned by the Canadian Hospice Palliative Care Association indicated that only 25-30% of Canadian family physicians say



they are “very comfortable” providing palliative or end-of-life care. 50% say they are “somewhat comfortable” and the remainder say they are “not very comfortable” or “not comfortable at all.”

There are generations of health care professionals who have had to educate themselves as best they could to meet the needs of people with life limiting conditions. Evidence suggests that the next generation is still not receiving the core education they will need to provide appropriate care to the dying.

One of the biggest challenges in assessing access to palliative care is defining what we mean by appropriate palliative care. Dame Cecily Saunders stated that Palliative Care is best delivered by an interdisciplinary team. Different patients and families will require different members of this team at different times. A basic team is made up of a primary care physician, nurse, and social worker, and many teams would include volunteers, spiritual care providers, pharmacists and others. Many patients will require either direct interaction with or advice (for the primary team) from a specialist palliative care team. Specialist palliative teams have the expert-level skills that are required to provide care in complex situations, to provide consultative support to generalist teams, to educate other physicians, and to conduct research. They are in regrettably short supply and are not available in many communities or for all settings of care.

Regarding the CIHI report on end-of-life in Atlantic Canada (data from 2007 – 2008), the commentary concludes that 59% of those who died in acute care hospital received palliative care, with New Brunswick having the highest rate at 64.4%. Having been the first and only full time Palliative Care Physician in New Brunswick in 2003, and being aware of the limited access to health care professionals who are adequately trained in palliative care in the rest of Atlantic Canada, I want to clarify this number. Patients are coded as being palliative in hospital if they are perceived to have had a palliative diagnosis at time of discharge. It in no way indicates if they received **appropriate** palliative care during their hospital stay.

Similarly, when attempting to measure access, it is important to be aware that the “number of palliative care beds” is not an accurate method of quantifying how much palliative care is done or available. Many places (nursing homes, hospitals etc) state that they

have palliative care beds, because it means (to them) that they provide palliative care. However, we know that there is often no training or experience that goes along with the bed, and that sometimes those beds are used for other purposes.

I left New Brunswick in 2004 after seeing a lack of support by the department of health for the development of a regional palliative approach to patients in hospital and in the community. I moved to Nova Scotia where they had started to develop regional programs. District Health Authority 4 (Colchester East Hants), which was accurately reported in the paper as having 77% access, was part of a federally funded Rural Palliative Home Care Project (1998-2001). Other regions in Nova Scotia were not part of the project and were left to start developing their own programs. To this day, there are great disparities in the province with regards to access to palliative care. In fact, in the Capital Health region, there are sections that do not have access to their palliative home care team and do not have access to home care nursing after 5pm.

On the bright side, we have introduced the educational materials “Learning Essential Approaches to Palliative and End of Life Care (LEAP)” across Atlantic Canada and have recently completed facilitator training to try to reach out to our health care colleagues to empower them to provide a “palliative approach” to patients with life limiting conditions with essential basic skills, including communication, pain and symptom management and prognostication.

Identification of appropriately trained Palliative Care specialists will become clearer with the College of Family Physicians of Canada certification for Family Physicians completing the year of added competency in Palliative Medicine and the newly developed Royal College of Physicians and Surgeons of Canada sub-specialty in Palliative Medicine.

Canada is blessed with a cadre of wonderful health care providers who do the best they can to provide end of life care. Unfortunately, many have not had the opportunity to have adequate training in palliative care. In many parts of the country they also often lack access to specialized palliative care teams to support them.

The Canadian Society of Palliative Care Physicians strongly urges further research to assess access. We are



currently working on a human resource project to try to help our country prepare to manage and support all Canadians as we enter a time in our history with a huge increase of people over 65 many living longer with multiple co-morbidities that complicate their normal dying process.

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