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The making of a myth: unreliable data on access to palliative care in Canada

Jocelyn Downie and Georgia Lloyd-Smith

Assisted death is now the subject of conversation in the media, in public meetings, and around kitchen tables across the country. And major law reform is in the air. A challenge to the *Criminal Code* prohibition on assisted dying will be heard by the Supreme Court of Canada in October 2014.¹ *An Act respecting End of Life Care* was recently passed by the National Assembly in Quebec.² And MPs Steven Fletcher and Manon Perreault recently introduced *An Act to amend the Criminal Code (physician-assisted death)*³ and *An Act to establish the Canadian Commission on Physician-Assisted Death* in the federal Parliament.⁴

A frequent part of many conversations about assisted death law reform is access to quality palliative care in Canada. A common refrain is “Don’t move to, or even talk about, assisted dying until access to palliative care is improved.” It is reasonable therefore to ask what the evidence is on access.

The “16-30%” claim

The Senate of Canada Report “Raising the Bar: A Roadmap for the Future of Palliative Care in Canada” stated that “[i]n 2008, a best estimate suggested that somewhere between 16-30% had some level of access, depending on location. That means upwards of 70% of Canadians still do not have access to even the most minimal form of palliative care.”⁵ Justice Smith in *Carter v. Canada (Attorney General)* concluded that “high quality palliative care is far from universally available in Canada”. She quoted a Crown expert witness who notes: “Unfortunately only 16-30% of Canadians receive palliative care as part of their life-threatening illness.”⁶ A recent peer-reviewed journal article “Barriers and facilitators to care for the terminally ill: A cross-country case comparison study of Canada, England, Germany, and the United States” published in *Palliative Medicine* in 2014 states that “the hospice palliative care utilization rate was 16%-30% of all deaths.”⁷ The report of the Royal Society of Canada Expert Panel on End of Life Decision-Making made the claim that “As many as 70% of Canadians lack access [to palliative care].”⁸ (12) A recent press release from the Canadian Medical Association on its National Dialogue on End-of-Life Care tour stated that “fewer than 30% of the Canadians who will die in 2014 will have access to palliative care.”⁹

Not surprisingly then, throughout the literature and other forms of media, the claim is made that only 16-30% of Canadians have access to palliative care (or, its derivative, 70% are without access). The “16-30%” claim has been widely accepted as a fact. But is it, in fact, true?

The origins of the “16-30%” claim

With a little bit of detective work, we were able to track down the source of this oft-repeated claim - a Hospice Palliative Care in Canada Fact Sheet produced by the Canadian Hospice Palliative Care Association (CHPCA) in 2010.¹⁰ It in turn references a report released by the Canadian Institute for Health Information (CIHI) in 2007.¹¹ The Fact Sheet claims that “only 16% to 30% of Canadians who die currently have access to or receive hospice palliative and end-of-life care services.” But there are significant problems with this claim:

- The CIHI report is based on data from 2003-04.
- The CIHI report relies on data from only four provinces – British Columbia, Alberta, Saskatchewan and Manitoba.
- The CIHI report only deals with the deaths of adults (19 years and older)
- Contrary to what the Fact Sheet suggests, the statistics on access to palliative care do not include those who had access to, but did not receive, palliative care.
- Contrary to what the Fact Sheet suggests, the statistics deal only with those who received palliative care in-hospital and died in hospital (i.e., “palliative hospital deaths”); they do not reflect palliative care at home or in non-acute care hospitals or more generally end-of-life care services outside the hospital. This matters because 42% of deaths occurred outside of the hospital setting and hospitals are not the only places where Canadians can receive palliative care. Provincial palliative care units, chronic care facilities, nursing homes, and residential hospices also provide end-of-life care. For example, there are over 250 beds in residential hospices across British Columbia where patients receive palliative care outside of the hospital setting.
- The “16-30%” figure used in the CHPCA Fact Sheet is a misrepresentation of the original data in the CIHI report. There is no table in the report from which a 16-30% range can be derived. One can derive a range of 13-16%, which is the range of percentages of all deaths that were palliative hospital deaths across the provinces. Alternatively, the range of all deaths that were palliative hospital deaths is between 5-28% (from 5% in Northern Manitoba to 28% in Brandon, Manitoba) when viewed at the level of the regional health authorities.
- The CIHI report itself notes that “[t]he method used to distinguish palliative care from acute care at the end of life is based on diagnosis and service codes that appear in the hospital record that may have been recorded differently in different provinces (for example, in the case of Manitoba these codes were used on palliative units only), **so these estimates should be interpreted with caution.**” (emphasis added)¹²

Alternatives to the “16-30%” claim

If one looks to the only other published empirical study of access to palliative care across causes of death in Canada, a different picture emerges. A CIHI report on end-of-life in Atlantic Canada (using data from 2007 to 2008) concluded that 59% of those who died in an acute care hospital received palliative care (with a range from 28.2% in PEI to 64.4% in New Brunswick and with a range from 8.5% in Queens, PEI to 77.2% in DHA4 NS).¹³ 30% of people who died in Atlantic Canada received some type of palliative care services during their final hospital admission. The percentage of all people who died who received hospital palliative care ranged from 13% in PEI to 36% in New Brunswick. These percentages of palliative care access are twice as high as those found in Western Canada (59% vs. 26% and 30% vs. 15%).

Studies restricted to patients dying of cancer also paint a significantly different picture. In 2013, CIHI reported that 45% of all cancer deaths in 2011-2012 occurred in acute care hospitals. Of these, 82% had a “documented palliative care diagnosis during their last admission.”¹⁴ A study of 402 cancer patient deaths in Toronto, Ontario found that 82% had access to palliative care before death.¹⁵

Furthermore, if one considers the changes that have occurred in palliative care since 2003-04, it would not be at all surprising if the rates of access to palliative care were much higher than in the frequently cited CHPCA Fact Sheet and CIHI report. The past 10 years have seen an increase in funding for palliative care research, new initiatives to improve access to palliative care, and improved education of health care professionals. For example, the federal government claims to have invested more than \$43 million in palliative care research since 2006.¹⁶ Educating Future Physicians in Palliative and End-of-Life Care was given \$1.25 million with the goal that “by 2008, all undergraduate medical students and clinical post-graduate trainees at Canada’s medical schools will receive education in PEOLC and graduate with competencies in these areas.”¹⁷ Palliative care training programs are also now available for nurses, social workers, pharmacists, and other health care workers. With all these new developments focused on expanding or otherwise affecting the availability of palliative care, it is likely that data from 10 years ago no longer reflects the current rates of access to palliative care in Canada.

Conclusion

And so, we are driven to the conclusion that the oft-repeated claim that only 16-30% of Canadians have access to palliative care should be retired. It is based on a misrepresentation of outdated data and it ignores the provision of palliative care outside of the acute care hospital setting. So, is there a better estimate to rely on? Sadly no. At this point, there is no way to know how many Canadians have access to palliative care in Canada. 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.

¹ Supreme Court of Canada Docket, online: <http://www.scc-csc.gc.ca/case-dossier/info/dock-regi-eng.aspx?cas=35591>

² Bill 52, *An Act respecting end-of-life care*, 1st Sess, 41st Leg, 2014, Quebec.

³ Bill C-581, *An Act to amend the Criminal Code (physician-assisted death)*, 2nd Sess, 41st Parl, 2013, Canada.

⁴ Bill C-582, *An Act to establish the Canadian commission on physician-assisted death*, 2nd Sess, 41st Parl, 2013, Canada.

⁵ Carstairs S. *Raising the bar: a roadmap for the future of palliative care in Canada*. Ottawa, ON: The Senate of Canada, 2010 at 12, online: www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf

⁶ *Carter v Canada (Attorney General)*, 2012 BCSC 886 at para 192.

⁷ CA Klinger, D Howell, D Zakus, RB Deber, "Barriers and facilitators to care for the terminally ill: A cross-country case comparison study of Canada, England, Germany, and the United States" (2014) 28:2 *Palliative Medicine* at 113.

⁸ U Schuklenk, JJ van Delden, J Downie, S McLean, R Upshur, D Weinstock. *The Royal Society of Canada Expert Panel: end-of-life decision making*. Ottawa, ON: Royal Society of Canada, 2011 at 12, online: <https://rsc-src.ca/en/expert-panels/rsc-reports/end-life-decision-making>

⁹ Canadian Medical Association. *Press release: Canadians Want End-of-Life Care Brought Out of the Shadows*. June 10, 2014, online:

http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Media_Release/2014/EOLReport-NewsRelease_FINAL.pdf. This statement is included in the press release but is not found in the CMA final report. It is also not supported by any reference.

¹⁰ Canadian Hospice Palliative Care Association. *Fact sheet: hospice palliative care in Canada*. Ottawa, ON: Canadian Hospice Palliative Care Association, 2010, online:

http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_march_2013_final.pdf

¹¹ Canadian Institute for Health Information. *Health care use at the end of life in western Canada*.

Ottawa, ON: Canadian Institute for Health Information, 2007, online:

<https://secure.cihi.ca/estore/productFamily.htm?pf=PFC876&lang=fr&media=0>

¹² *Ibid*, at 27.

¹³ Canadian Institute for Health Information. *Health care use at the end of life in Atlantic Canada*.

Ottawa, ON: Canadian Institute for Health Information, 2011, online:

<https://secure.cihi.ca/estore/productSeries.htm?pc=PCC569>

¹⁴ Canadian Institute for Health Information. *End-of-life hospital care for cancer patients*. Ottawa, ON: Canadian Institute for Health Information, 2013 at 2, online:

https://secure.cihi.ca/free_products/Cancer_Report_EN_web_April2013.pdf

Of note, the CIHI did not have access to information to determine whether patients who were documented as palliative during their last admission actually received palliative care services.

¹⁵ S Hales, A Chiu, A Husain, M Braun, A Rydall, L Gagliese, C Zimmermann, G Rodin, "The quality of dying and death in cancer and its relationship to palliative care and place of death" (2014) *Journal of Pain and Symptom Management*, at 4.

¹⁶ Canada. Health Canada. *Helping to facilitate training in palliative care for front-line healthcare providers*. Ottawa, ON: Health Canada, 2014, online: http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/_2014/2014-026-eng.php

¹⁷ Canada. Health Canada. *Canadian Strategy on Palliative and End-of-Life Care: Final Report*. Ottawa, ON: Health Care Canada, 2007, online: http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2007-soin_fin-end_life/index-eng.php. All 17 medical schools now train their students in palliative care. Carstairs S. *Raising the bar: a roadmap for the future of palliative care in Canada*. Ottawa, ON: The Senate of Canada, 2010 at 15, online: www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf