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Position Paper

Palliative Care/End of Life Care: What do we need?

Many studies of palliative care point out Canadians' stated preference for ending their days at home. These studies underline the increasing demand for palliative or end of life care, especially as seniors now comprise 16% of our population and in the next twenty years the proportion will be 23 – 25%. Studies also show that access to this kind of care varies enormously depending on where patients live. Despite awareness of preferences, of the increasing interest in palliative and end of life care, plus the lower cost of this type of care, there is still a disconnect between our health care system and what is available to patients and their families.

Taking the point of view of the patient is the key. Although there is now debate on physician assisted dying and what regulations should emerge, no one should be forced to contemplate this as an option because there is a lack of good quality, accessible palliative/end of life care. How we accomplish the latter requires consistent data from across the country, with well thought out policies and procedures, and adequate resources. There should be a Canada-wide set of standards and policies related to palliative care practices across the provinces and territories instead of the current patch work. In addition, the oft-cited problem of inappropriate prescribing of some medications to seniors needs to be addressed in these policies and practices.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” According to the Canadian Cancer Society’s “Right to Care: Palliative Care for All Canadians” (2016), palliative care is very important as part of a continuum of care that can be started early in

a disease to address physical and non-physical symptoms. It involves a team approach of health care providers who support patients and families. End-of-life-care is a component of palliative care but it focuses on dying. While recognizing the distinctions, for the purposes of this paper, the term, “palliative care” will be used more generally, including end-of-life.

A patient can receive palliative care in many locations: in hospitals, long-term care facilities, hospices or at home. Hospitals can have palliative care beds, or sometimes special units. However, not all deserving hospital patients receive palliative care, especially in acute care or intensive care wards where 70% of patients die. (Canadian Hospice Palliative Care Association, 2014) Research is demonstrating the value of palliative care being available outside hospitals in long term care homes, hospices or as integrated palliative care programs supporting home care. In the Canadian Medical Association’s “Palliative Care: CMA’s National Call to Action” (May 2015), eight different leading organizations were featured, none of them based in a hospital. For example, the Colchester East Hants Health Authority Integrated Palliative Care Program in Nova Scotia, begun in the late 1990s, does support patients at home as well as in long term care facilities. It relies heavily on nurses working closely with primary care physicians and palliative care specialists to obtain the best results in pain and symptoms management. The Nova Scotia program meets the standards of the Canadian Hospice Palliative Care Association and the Canadian Hospital Accreditation Service. Consultation services with or by experts are available in the community, at the local hospital and health centre. Consultation teams involve palliative care doctors, nurses and social workers who collaborate closely with the Hospice Society that has two social workers on staff. Also the Society is key in training volunteers and overseeing student placements. These programs derive their funding from the Nova Scotia Dept. of Health and Wellness.

Outside the hospital setting, long-term care facilities, home settings and hospices are set up specifically to treat patients dealing with serious diseases. They provide home-like conditions where patients receive less interventionist types of care aimed at controlling pain and anxiety. Most often these patients have advanced cancer (80-85% in Ontario; 80-90% in Nova Scotia) (Canadian Cancer Society, 2016, 3). But, according to the Canadian Hospice Palliative Care Association (CHPCA) (2014) only 16 to 30 percent of Canadians have access to hospice palliative care or end of life services, depending on their location.

The CHPCA claims that the benefits of palliative care include: better quality of life, improved symptom control, higher levels of satisfaction and in some cases longer life. Other positive features include lower costs. The Ontario Auditor General’s 2014 report estimated the cost of care in the last month of life at \$1100/day in hospital, \$770 in a palliative care unit, \$460 in hospice and less than \$100 at home. Home-based palliative care does, however, involve significant unpaid care-giving costs, which in Ontario has been estimated at 77% of the total costs for palliative care. In 2009, the estimated economic contribution of family caregivers in Canada was between 25 and 26 billion dollars. (Statistics taken from CHPCA, 2014) Several commentators on an early draft of this paper pointed out the heavy burden placed on spouses/partners, children and friends who care for loved ones at home. They need respite services, better leave policies and more resources for supplies such as lifts and other assistive devices.

Family care-giving introduces a whole new element to family life. Individuals often miss work, use their own personal savings, and may experience negative effects on their physical and mental health (CHPCA, 2014). They frequently need to undertake a wider range of tasks in an environment with less support from professional caregivers. Note also that all provinces have some form of palliative drug coverage for home care since 2012, and provide legislation to protect jobs for those taking unpaid compassionate care leave (eight weeks except in Quebec which allows twelve). The federal government has recently extended its compassionate care benefits program to 26 weeks. Internationally Canada is not highly ranked, however, placing 27th out of 40 countries surveyed. (Economist, 2010).

It now seems absolutely clear that we need National Leadership for a national strategy for palliative and end-of-life care, in co-operation with provincial and territorial governments. There are still no common standards or approaches; indeed we do not even collect data in a consistent manner. Health care professionals can still be better trained in palliative care. And if we want a system that is accessible to all, we need to provide sufficient resources so that palliative care becomes a real choice for patients who want it. This is a real opportunity for Federal collaboration and leadership to enhance comfort and quality of life for Canadians experiencing a serious, life-threatening illness.

SOURCES:

Canadian Cancer Society, “Right to Care: Palliative Care for All Canadians” (January 12, 2016)

Canadian Hospice Palliative Care Association, “Fact Sheet: Hospice Care in Canada” (March 2014)

Canadian Medical Association, “Palliative Care: CMA’s National Call to Action, 2014-15” (May 2015)

Economist Intelligence Unit, “The Quality of Death: ranking end-of-life care across the world,” 2010

www.who.int/cancer/palliative/definition/en/

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