

Growth of palliative care programs - how are we doing?

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There is no lack of literature evidence suggesting that from a global and local perspective there has been notable success in the development and growth of palliative care programs. This is well illustrated by a few recent publications (1-3).

A global mapping update of palliative care development reports that in 2011 136/234 countries (58%) had established some hospice-palliative care services, representing an increase of 21 countries since 2006 (1). Interestingly the most significant gains are in Africa. Unfortunately advanced integration of palliative care within the health care system has been achieved in only 20 countries globally (8.5%) even though there is some indication of interest in palliative care on the part of national governments and policy makers. The United States (US) and Canada are listed in the highest category of development and integration (Level 4b advanced). The authors concluded that “Despite increasing calls for palliative care to be recognized as a human right, there remains much to be done before palliative care is accessible equitably and globally.”

The extent of progress achieved in the US to warrant the highest category listing is illustrated to varying degrees by two contrasting publications (2,3).

Cancer centers and other health care organizations have apparently responded to the advocacy of need by developing palliative care programs in academic and community settings. A notable example over the last decade has been the University of Texas M. D. Anderson Cancer Center in Houston which is an example of an institution that has integrated palliative care into both the inpatient and outpatient settings (2). This report describes the growing pains of an integrated palliative care program over 10 years that includes an inpatient Palliative Care Unit, a mobile consultation service, and an outpatient supportive care clinic. During this time all service provision increased

dramatically with the inpatient consults the most impressive example going from 73 consults in the first year to 1880 in the 10th year. The authors comment on some interesting lessons learned including the need to plan for growth, a strategy to deal with resistance from detractors, and the advantages of using the terminology “supportive care” rather than “palliative care” to limit a perceived barrier to referral. The issues of earlier referral and integration of palliative care in the treatment of patients with life limiting illnesses, and the inclusion of a primary care component to allow palliative care providers to provide a more selective secondary supportive care role are important questions raised for consideration.

The second report addresses the evolution of palliative care in the US in response to demand rather than systematic health care service planning (3). The authors propose an emerging model of integrated palliative care service delivery named community based palliative care (CPC). Community based hospice has been the original foundation of palliative care development with the more than 3,600 hospices in the US representing a 110 fold increase over the last 30 years. The recognition of need for hospital palliative care service has seen a 138% increase from 2000 with close to 2/3s of hospitals now providing some access to care. However the majority of inpatient programs do not have any community integration to ensure some continuity of care on discharge home. Outpatient palliative care clinics have been developed and proposed as a solution but clearly have limits and do not provide a comprehensive solution to seamless patient centered care. The authors assert that hospice, inpatient and outpatient palliative care are component parts that require assembly into a continuum and that CPC is the foundation for this development. The acronym CPC is extended to stand for: - Consistent across transitions;

Prognosis-independent; Collaborative and Coordinated. They conclude that considerable workforce, cultural, institutional, and financial barriers presently exist which will prevent implementation of the CPC model.

While applauding the wisdom and value of the CPC model it is worth considering how Canada achieved success using exactly this approach in the 1990s. A publication from 1999 (4) described how in Edmonton and other Canadian cities the limited integration of community based palliative care services was a major obstacle to patients. Most cancer patients were dying in acute care facilities after relatively long admissions. The Edmonton Regional Palliative Care Program was established in July 1995 with the aim of increasing access of patients with terminal cancer to palliative care services, decreasing the number of cancer-related deaths in acute care, increasing the participation of family physicians in the care of terminally ill patients in the community, and providing these physicians with adequate support. The program included a 14-bed tertiary palliative care unit (PCU), a weekly multidisciplinary palliative care clinic in the cancer centre, hospice PCUs in 3 continuing care hospitals (56 beds), and consultant palliative care physicians and nurses to provide consultations at home, in the 3 hospices, and in the regions 5 hospitals. A registry of family physicians willing to provide primary palliative care was initiated and widely publicized among the city's family physicians. An increased fee for the delivery of palliative care at home or in hospice PCUs was established for family physicians by the provincial funding agency. The outcome in comparing the pattern of care and site of deaths before the establishment of the program (1992/93) and the second year of operation (1996/97) was a significant decline in cancer-related deaths in acute care facilities from 1992/93 to 1996/97 [86% (1,119/1,304) *vs.* 49% (633/1,279)] ($P \leq 0.001$). At the same time inpatient days decreased from 24,566 in 1992/93 to 6,960 in 1996/97. The cost of care was addressed in a subsequent publication (5) which recognized that 2 Canadian cities, Edmonton and Calgary, were among the first programs to have comprehensive, coordinated and community-based palliative care services integrated into the health care system. Administrative databases were linked to identify 16,282 adults who died of cancer between 1993 and 2000 and measure healthcare resource utilization. Palliative care services increased from 45% to 81% of cancer patients during the study period and cost neutrality to the health care system was observed. Substituting less hospital time for more community care in the home and hospice PCUs accounted for the bulk of the savings to offset the increased

service provision. The Edmonton program has now evolved to meet the growing need to incorporate non-cancer palliative populations in all locations of care (6,7).

It seems reasonable to conclude that not all countries listed in the "Level 4b advanced" (1) category have been created equally. The differences between countries in health care system organization that have facilitated the development of integrated palliative care service models in Canada while serving as a barrier in the US would appear to be an important focus for understanding in advocacy for future growth in palliative care programs internationally.

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